DOCUMENT RESUME

ED 308 420 CG 021 740

AUTHOR Ansello, Edward F.; Rose, Thomas
TITLE Aging and Lifelong Disabilities: Partnership for the Twenty-First Century.
INSTITUTION Maryland Univ., College Park. Center on Aging.
PUB DATE 89
NOTE 88p.
PUB TYPE Collected Works - Conference Proceedings (021)

EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS *Aging (Individuals); Cooperative Planning; Delivery Systems; *Developmental Disabilities; *Human Services; Institutional Cooperation; Mental Retardation; *National Programs; *Older Adults; Public Policy; *State Programs

ABSTRACT

This document contains presentations from the Wingspread Conference, a conference held in June 1987 to examine issues posed by the increasing longevity of older Americans with mental retardation and developmental disabilities. An executive summary and the following papers are included: (1) "Aging and Lifelong Disabilities: Problems and Prospects" (Edward Ansello and Thomas Rose); (2) "The Aging and Disabilities Partnership" (Edward Ansello); (3) "On Aging and Lifelong Disabilities: A New Response" (Jean Elder); (4) "The Aging Developmentally Disabled as a Dimension of All Our Goals" (Jack Ossofsky); (5) "Introduction to Aging and Lifelong Disabilities: Context for Decision-Making" (Marsha Mailick Seltzer); (6) "Barriers to and Opportunities for Cooperation Between the Aging and Developmental Disabilities Service Delivery Systems" (Robert Gettings); (7) "State Partnerships to Enhance the Quality of Life of Older Americans with Lifelong Disabilities" (Daniel Quirk); (8) "Best Practice for Integrating Service Delivery to Older Persons with Developmental Disabilities" (John Stokesberry); (9) "What's Happening at the State Level: Technical Problems, Administrative Solutions" (M. Doreen Croser and others); (10) "Federal Legislation and Strategies for the Future: A View from the Senate" (Janet Pisaneschi); (11) "A National Agenda for the Future: Action Steps and Recommendations" (Robert Gettings); and (12) "National Policy Goals for Older Persons with Developmental Disabilities" (Donna McDowell). Also included are summaries of discussion groups on decision making and public policy in aging and disabilities and on strategies and recommendations. The epilogue discusses public policy implications. References for further reading and programmatic information on the conference are appended. (NB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED308420

Aging and Lifelong Disabilities

Partnership for the Twenty—First Century

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☒ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Edward F. Ansello

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

The Wingspread Conference Report

CG 021740

Edward F. Ansello and Thomas Rose
University of Maryland Center on Aging

Aging and Lifelong Disabilities: Partnership for the Twenty-First Century

EDWARD F. ANSELLO
The University of Maryland Center on Aging

THOMAS ROSE
The University of Maryland Center on Aging

Aging and Lifelong Disabilities: Partnership for the Twenty-first Century,
by Edward F. Ansello and Thomas Rose, is a publication of The University of Maryland Center on Aging

Editor: Susan Coombs Ficke

Design and Production by: Elder Press, a program of the Elvirita Lewis Foundation ©1989 by The University of Maryland Center on Aging

Printed in USA
by
ElderPress
A Project of the Elvirita Lewis Foundation
Palm Springs, California
1989

TABLE OF CONTENTS

Preface vii
Acknowledgements ix
Elvirita Lewis Foundation xi

EXECUTIVE SUMMARY 1

PART ONE: INTRODUCTION
Aging and Lifelong Disabilities: Problems and Prospects 9
Edward F. Ansello and Thomas Rose
The Aging and Disabilities Partnership 13
Edward F. Ansello
On Aging and Lifelong Disabilities: A New Response 15
Jean K. Elder
The Aging Developmentally Disabled as a Dimension of All Our Goals 17
Jack Ossofsky

PART TWO: BUILDING PARTNERSHIPS
Introduction to Aging and Lifelong Disabilities: Context for Decision-Making 23
Marsha Mailick Seltzer
Barriers to and Opportunities for Cooperation Between the Aging and Developmental Disabilities Service Delivery Systems 27
Robert M. Gettings
State Partnerships to Enhance the Quality of Life of Older Americans with Lifelong Disabilities 30
Daniel A. Quirk

PART THREE: DECISION-MAKING AND PUBLIC POLICY IN AGING AND DISABILITIES: PROBLEMS, DILEMMAS, AND BARRIERS
Management and Administration 35
Service System Development 36
Advocacy and Public Awareness 39
Public Policy 40

PART FOUR: EFFECTIVE STATE RESPONSES

Best Practice for Integrating Service Delivery to Older Persons with Developmental Disabilities 43
John L. Stokesberry

What's Happening at the State Level: Technical Problems, Administrative Solutions 46
M. Doreen Croser, Julie Ann Jackson, B. Stockton Clark, and Paul D. Cotten

PART FIVE: STRATEGIES AND RECOMMENDATIONS: POLICIES, PLANS AND PROGRAMS

Moving Forward: Action Steps and Ideas for Advancement of Management and Administration 49
Service Systems Development: Strategies for the Future 50
The Need for Advocacy and Public Awareness 52
Creating a New Public Policy Framework 53

CONCLUSION: PUBLIC POLICY IMPLICATIONS

Federal Legislation and Strategies for the Future: A View from the Senate 55
Janet Pisaneschi

A National Agenda for the Future: Action Steps and Recommendations 58
Robert M. Gettings

National Policy Goals for Older Persons with Developmental Disabilities 60
Donna McDowell

WINGSPREAD — AN EPILOGUE 65

Further Reading 69
The Wingspread Conference 73
Conference Sponsors 73
Wingspread Planning Committee 74
Speakers 75
Discussion Leaders, Moderators and Resource Persons 76
The Conference Program 77
Conference Participants 78

Preface

Aging and Lifelong Disabilities: Partnership for the Twenty-first Century explores the emerging challenges and critical issues posed by the increasing longevity of older Americans with mental retardation and developmental disabilities (MR/DD).

That state government leaders from the two systems of aging and developmental disabilities should meet grows naturally out of the emerging intersection of their clientele: more adults with developmental disabilities are living to later life; more elders with special needs are requesting services from the aging network. Conditions of need for services are real.

Historically older individuals with lifelong disabilities have either been cared for by their parents and families at home, or have spent many years in institutions. In the past they have typically not survived to old age, nor have they interacted with systems of community services. As a result, MR/DD professionals have had little experience with people with disabilities who are elderly; and because adults with developmental disabilities have, for the most part, not lived to late life, aging network professionals have had little experience in providing programs or services for elders who have disabilities.

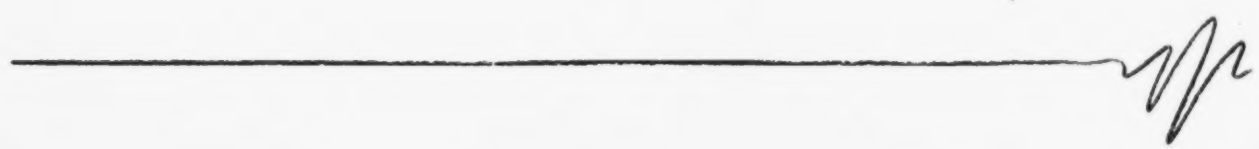
In short, there is little history of interaction between the aging and developmental disabilities "systems" of researchers, policy makers, planners and providers in organizing and delivering services to meet the needs and alleviate the problems of older people with lifelong disabilities.

The challenges are many. How do providers plan services for an influx of older adults with disabilities who have, until this point, been outside the community services network, having been cared for by their parents or having spent most of their lives in large institutions? How large is the population in question? What models of research and practice can be brought to bear? How might members of our society with disabilities who are elderly be integrated into community senior centers, adult day care centers, and other similar programs developed for older Americans? How can programs authorized under the Older Americans Act be made more responsive in providing the kinds of community services that are beneficial to older citizens with lifelong disabilities? What actions should be initiated to build upon, encourage and maximize the contributions of adults with developmental disabilities to others in the community, whether disabled or not, whether old or not? How can the human and material resources of one system benefit the clientele of the complementary system?

Recognizing that state policy-makers, as well as program planners, practitioners, aging and MR/DD advocates, and others, need current information on the rapidly growing and heretofore-overlooked segment of our society represented by older people with lifelong disabilities, The University of Maryland Center on Aging asked outstanding scholars and national spokespersons from the two disciplines to develop papers representing their best thinking regarding projections for the future and their implications. In addition, experienced state leaders from across the country were asked to analyze some of the major obstacles to progress and to recommend actions for changing existing policies and service systems to meet the needs of the future. In the harmonious setting of the Frank Lloyd Wright-designed Wingspread Center leadership from the two human service systems, aging and developmental disabilities, and worked together. In an intensive agenda participants focused on the essentials: a **vision** for the future and practical plans of **action.**

In designing the Wingspread Conference, the ultimate focus was on enhancing the capacity of state governments to develop policy and to provide for comprehensive, coordinated service systems to meet the diverse needs of older persons with lifelong disabilities. The objectives were to:

- Create an awareness of national and state policies that facilitate or reinforce the ability of human service systems to meet the needs of older persons with developmental disabilities.
- Communicate current research, best practices, and strategies for implementing, financing, and managing services and opportunities for older persons with developmental disabilities, including contributions by these adults to others in the community.
- Foster collaboration between state units on aging and MR/DD agencies in the development of services and opportunities for older persons with developmental disabilites.



- Promote effective development, implementation, and management of programs and services targeted to older persons with lifelong disabilities.
- Develop and widely disseminate a practical policy-oriented book based on the Conference that includes background information, recommendations for action, and suggestions for national and state policy development.

Aging and Lifelong Disabilities: Partnership for the Twenty-first Century is not the last word on these subjects but we hope that for readers it will be a step in the direction of increased awareness of and attention to the needs of our society's older members who have endured lifelong disabilities.

Acknowledgements

Aging and Lifelong Disabilities: Partnership for the Twenty-first Century was made possible through the encouragement and generous contributions of the Keland Endowment Fund of the Johnson Foundation, The Joseph P. Kennedy, Jr. Foundation, The Elvirita Lewis Foundation, the National Institute on Aging, The Pew Charitable Trusts, the President's Committee on Mental Retardation, and the Retirement Research Foundation. To these public-minded organizations, we extend our sincere thanks.

The University of Maryland Center on Aging owes a considerable debt to the National Association of State Units on Aging and the National Association of State Mental Retardation Program Directors, Inc., for their invaluable assistance, technical consultation, and participation in making this Conference possible. We also want to express particular appreciation to the many contributors who have allowed their papers and commentary to be adapted for general distribution to other committed professionals involved in serving the aging with lifelong disabilities. Their cooperation enables us to share their knowledge and experience in more permanent form and to a broader audience.

Edward F. Ansello, Ph.D., Associate Director
The University of Maryland Center on Aging

Thomas Rose, Ph.D., Research Associate
The University of Maryland Center on Aging

The Elvirita Lewis Foundation

The Elvirita Lewis Foundation has supported the publication of this report because we hope it will raise awareness of the potential contributions of handicapped and disabled individuals, young and old. Our foundation was created in 1975 to promote the belief that older people constitute one of the great untapped human resources for resolving social problems. We believe that very frail older persons, regardless of the list of incapacities they might have, still also have capacities. These capacities and the general perspicacity of older people should be recognized in designing socially and psychologically valid social services.

The Elvirita Lewis Foundation believes that individuals with disabilities and handicaps must be viewed in the same way, building upon their capacities rather than dwelling upon their infirmities. We have found that the old and young, including those with disabilities and handicaps, can be allies in improving the quality of their lives. Assisting one another, they raise their own self-esteem while encouraging one another's growth.

Some examples come to mind. Through our Senior Companion Program we have recruited and trained healthy older people to help other more frail or disabled elders stay in their own homes, and out of long-term care institutions. We found that regular visits, assistance with writing checks, shopping, making meals, and facilitating socialization were all useful ways our Senior Companions could help to improve the self-esteem and independence of frail older people. We discovered, however, that this was not enough. So we created "capacity networks," bringing two or three Senior Companions together with a dozen or so older frail clients, in order to get the group members involved in helping each other.

A Senior Companion helped two frail, elderly women to enrich the lives of others. The first grew roses, County Fair award winners. The second, who was homebound, made stunning flower arrangements. The Companion transported these two women to a senior center where they taught others how to grow roses and arrange them. The healthier women at the center now take these flower arrangements to elders confined to hospitals or nursing homes. The expense was minimal, but the rewards in human terms were spectacular.

In another "capacity network" an elderly woman, in a wheelchair but with excellent eyesight, calls another member who is blind each day to read her the morning paper and a chapter from a novel. Encouraged by and connected to others in her network, this blind woman who was a weaver now makes beautiful tapestry bookmarks which a third member distributes to other elders.

We could cite many other examples, but these two demonstrate that the future development of services for elders and for those who have disabilities must include them in the planning, oversight, **and** delivery of these services. At the Elvirita Lewis Foundation we hope this report inspires the development of appropriate "capacity networks" involving disabled people as informal service providers to one another.

Executive Summary

Background

There is an emerging need in the United States for health, social, and long-term care services, created by the increasing longevity of citizens who have endured lifelong disabilities. In numbers previously unimagined, people with mental retardation and developmental disabilities (MR/DD) are surviving into old age and, in many instances, are outliving their parents and family who have been providing lifelong informal support for them.

Certain problems are already manifest. Of these, the most fundamental is the scarcity of information about **who** the aged with lifelong disabilities are, **where** they live, and **what** needs they have once they reach old age. The population of adults with developmental disabilities is growing notably and is remarkably diverse. Studies have suggested that more than 60 percent of those with developmental disabilities are currently not being served by the MR/DD service system; that is, they are often aging in place with their parents in two-generation geriatric families.

Across the nation, states are becoming more aware of and more concerned about the well-being of their citizens who are both aging and lifelong disabled. As that concern grows mechanisms and policies for serving elderly persons with lifelong disabilities will improve. However, it is unlikely that we will have time for a gradual evolution. Already some estimates put the number of adults with lifelong, developmental disabilities at as many as 10 of every 1000 persons over age 60. Conditions of need for services are real and they are present. It is time for concerted efforts between the aging network and the DD/MR system to clarify policies, identify and remove obstacles to cooperation, and initiate services and programs that focus on the intersection of their two systems, i.e., the elder with lifelong disabilities.

To assist states in planning their responses to the current and emerging needs of older citizens with lifelong disabilities, The University of Maryland Center on Aging invited leaders from across the country representing state developmental services/mental retardation programs and state offices on aging to participate in a three-day working conference in June 1987 at the Wingspread Conference Center in Racine, Wisconsin. The papers and summaries of work group discussions in this book contain some of the most innovative thinking and recommendations for action in the field today. It is hoped that they will help to stimulate both better understanding of the needs of this population and clearer vision regarding the obstacles to be overcome and the strategies for effective policies and practices.

The University of Maryland Center on Aging acknowledges the vital support of the National Association of State Units on Aging, the National Association of State Mental Retardation Program Directors, Inc., the Joseph P. Kennedy, Jr. Foundation, the Elvirita Lewis Foundation, the Pew Charitable Trusts, the Retirement Research Foundation, the President's Committee on Mental Retardation, the National Institute on Aging, and the many consultants and advisors who have given generously of their time and their knowledge. The convergence of so many organizations to sustain our work is symbolic of the cooperative efforts that will be required to address the demands that elders with lifelong disabilities present.

Definitions of Aging and Lifelong Disabilities:

A **developmental disability** is currently defined under the Developmental Disabilities Assistance and Bill of Rights Act as a severe, chronic disability of a person which:

(A) is attributable to a mental or physical impairment or combination of mental and physical impairment;
(B) is manifested before the person attains age 22;
(C) is likely to continue indefinitely;
(D) results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency; and
(E) reflects the person's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Developmental disabilities (DD) may include cerebral palsy, blindness, deafness, mental retardation, orthopedic handicaps, multiple disabilities and other lifelong conditions.

Mental retardation is defined as "significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period" (American Association on Mental Deficiency).

Aging is more difficult to define. Research at The University of Maryland Center on Aging discovered about a dozen chronological ages associated with the onset of old age in the developmental disabilities literature. Within the aging network age 60 is most commonly used as the onset of old age because entitlements under the Older Americans Act are pegged to age 60. Consensus is needed regarding the chronological demarcation by which to define elderly status for those with developmental disabilities. Once definitional clarity is achieved, researchers will be able to study the prevalence and characteristics of that segment of the population which is both elderly and lifelong disabled, and planners will be better able to anticipate demand for and appropriateness of services. Longitudinal studies are needed to track the aging process in this group and to distinguish "cohort" or birth group effects from individual differences.

Despite shared concerns and significant similarities between older Americans in the mainstream of society and those with lifelong disabilities, there are striking differences. For example:

- Individuals with developmental disabilities usually require an array of services over their entire lifetime, in contrast to chronically disabled people who are disabled later in adulthood or, in the case of elderly individuals, who need services only during the waning years of their life.
- The person with a developmental disability needs a changing array of services during different periods in his or her life, in contrast to an elderly individual or a person disabled during adulthood who typically requires a gradually increasing intensity of services on growing older.
- Due to the early onset of disability among the developmentally disabled, there is less likelihood of residual life skills which help to compensate for any impairments they may have later in life.
- While an individual with developmental disabilities usually requires a variety of specialized educational, vocational, and habilitative services oriented toward the acquisition of basic life skills (self-care, socialization, gross and fine motor development, etc.), individuals who are disabled later in life need a variety of specialized rehabilitation services aimed at restoring, reteaching, or substituting for previously existing skills.

Services Sectors

Elders with lifelong disabilities can participate in services and programs through three types of systems. These are: 1) **the age-integrated MR/DD service sector** (such as group homes and sheltered workshops) which include some elderly clients with mental retardation and developmental disabilities, along with younger adult service recipients, 2) **the generic aging service sector** (such as senior centers and nutrition sites) in which the elderly with lifelong disabilities participate in programs designed for the general (non-disabled) elderly population, and 3) **the specialized service sector** for elderly persons with lifelong disabilities which includes services designed exclusively or primarily to meet their needs.

Cross-Cutting Issues

Policy makers and leaders in the fields of aging and developmental disabilities should be aware of issues that traverse the differences between mainstream adults who grow old and adults with developmental disabilities who grow old, and should be aware of concerns that each system of clientele, services, and providers encounters in common. These "cross-cutting" issues highlight the similarities that may help forge a partnership between the systems that is built on a **vision** for the nation, a vision that emphasizes growth and opportunity, one that does not pit one generation's needs against another nor one group against another within the same generation.

Marginality. Both the elderly and those with developmental disabilities have historically been outside the mainstream of society, although certainly to different degrees. Aging in this country has traditionally meant progressive disenfranchisement, sometimes forced separation from the "contributing sector" of the economy, while today's elders with

developemental disabilities have experienced a lifespan of segregation from the social flow. Overcoming these centrifugal social forces is basic for each group's development.

Family Caregiving. Care provided at home by the family has historically been, and will prospectively be, associated with both groups. Adults with developmental disabilities have, in the main, been cared for by their families in the community, rather than by professional providers in formal, institutional settings. At the same time, estimates are that 70% to 80% of the chronic or continuing care received by formerly mainstream and now frail, dependent elders is provided by family members, unassisted and often times unrecognized by the formal care network. Supporting and reinforcing the irreplaceable resource of family caregiving is central to the functioning of both the DD/MR and aging systems.

Contributions by Clientele. Leaders in each system have separately discovered the valuable contributions that their "clientele" can make to others. The aging network now programs for peer counseling by elders, intergenerational activities involving children and elders, social or humanitarian aid by and to elders as in meals-on-wheels and home chore services. Similarly, the DD/MR system has become accustomed to contributions by mentally retarded adults as assistants to elders in nursing homes and in adult day care centers, by handicapped adults as companions to frail elders in senior centers and to children in educational settings. Enhancing the contributions of one system's clientele to the other would benefit both systems and help dispel the stereotypes associated with marginality.

Heterogeneity. Diversity or heterogeneity typifies both the DD and aging populations. It is axiomatic within the aging field that as a cohort (birth group) grows older, its membership becomes less alike. This is no less true among adults with developmental disabilities, whether mentally retarded and non-retarded. One encounters a range of abilities and needs among elders of the **same** age with the same developmental disability, to say nothing of differences in abilities and needs between individuals of **different** ages with the same disability. At the present time, for example, elders classified as mentally retarded are in general less impaired than their younger counterparts, because the former were often mislabeled early in life and because their more severely retarded members failed to survive to later life. The differences between individuals, indeed, their their very individuality, need to be acknowledged when planning programs like intergenerational or senior center activities, whether the person in question is a mainstream adult grown old or an elder with lifelong, developmental disability.

Goal Clarity. Both systems are in flux, their populations changing. Thoughtful leaders within each network ask, "Where are we going?" For example, does the DD system establish a new "product line" for its DD aged, separate from its traditional age-integrated (serving all ages) approach and separate from the generic (serving all elders) approach of the aging network? Similarly, does the aging network itself develop a system parallel to DD services in order to serve the increasing numbers of elders who suffer late-life disabilities like Alzheimers disease? Should the two systems share an agenda and coordinate resources (people, time and money) on given advocacy issues? Decision-making about goals is pressing and will have far-ranging consequences for both systems.

Education for Providers. There is immediate need for improved education and training for the two systems' professionals and paraprofessionals; for more awareness of the increasing intersection of systems without a history of previous interaction; for extensive cross-training about the philosophy, terminology, funding streams, practices and other specifics of the complementary system, so that appropriate referrals and resources are employed. Education and training should inculcate creative problem-solving, using the combined resources of the two systems, in order to rearrange "mental geography" which restricts what professionals and paraprofessionals see as their domain or mandate. Education and training should aim to stimulate interagency and intersystem coordination, such as conferences, joint research and planning on cross-cutting issues like transportation, elder abuse and family caregiving. Ironically, because we are **not** yet in a period of crisis regarding the intersection of

aging and developmental disabilities, some of the incentive for creative problem-solving and innovative intersystem action is absent.

Exchange of Services. Each system possesses resources, human and material, of potentially great value to the clientele of the complementary system. Senior centers and other generic aging-related programs can be meaningful, enjoyable experiences for elders with lifelong disabilities, but usually "don't count" as satisfying the DD elder's requirement of a given number of hours of active treatment/programming a day. Similarly, DD day facilities have the programs and experienced personnel that might benefit formerly mainstream adults who are now behaviorally and cognitively unstable because of Alzheimer's disease. But eligibility criteria present an obstacle. The two systems have answers to the other's needs, if criteria and requirements can be addressed creatively.

Governmental and Programmatic Obstacles

Need for more knowledge. Too often, state aging and MR/DD leaders and staff know little about the complementary system. Increased knowledge and heightened awareness about each other's authorities, budgets, policies, implementing structures, functions, priorities, mandates, and target populations are necessary if the states and the nation are to make progress toward achieving improved services and service integration on behalf of older Americans with lifelong disabilities.

The aging and the MR/DD service delivery networks have markedly different organizational structures. While the Older Americans Act of 1965 and its amendments have fashioned a fairly standard model of operations for aging-related service delivery within the states, there are a half dozen or more organizational typologies for MR/DD services among the several states. These differences dictate sensitivity to the state system in operation.

Aging and MR/DD agencies have different means of regulating and monitoring their respective service systems. Because of the interplay between legislative policies and regulations, closer coordination and communication between agency staffs are needed to improve statewide planning so that overlaps and gaps between and among programs can be identified.

In-service training of professionals, para-professionals, and informal care providers—and education of the public at large—are extremely important in terms of eliminating stereotypes, myths, and other barriers serving to impede effective service delivery to older persons with lifelong disabilities. At the same time, attention must be directed to finding agreement on definitions, language, and terminology used by both the aging and the MR/DD systems.

Need for Creative Use of Resources. Money poses a real problem, both the lack of it and the restrictions placed on its use. Creative applications of available monies must be realized in order to serve older Americans with lifelong disabilities. Existing services fail to meet the needs of a great many of these citizens, in large part due to categorical program restrictions and restrictions in eligibility, such as age criteria. States are caught in the dilemma of funding following the service, rather than following the people who need assistance.

Currently more than 60 percent of the older population with developmental disabilities are not being served by the MR/DD service system. More case management services are needed to forestall a potential crisis when the aging parents are no longer able to care for their mature adult offspring.

The aging network and the DD/MR system are bureaucracies which heretofore have not intersected. The separation of current services which are based on categorical programs and separate funding streams and are restricted to serving preferential client groups has kept state aging and MR/DD service systems separated, too.

The extent to which integration of services can be carried out on behalf of older persons with developmental disabilities will be affected by Medicaid policy. Recently, Medicaid has provided limited coverage of community-based health and social services through the Home and Community Based Waiver Program. However, expansion of this demonstration to a full federal entitlement program, accessible to all low-income people who need long-term care, will be very costly and is not likely in today's political and economic climate without concerted efforts.

There is a need to rethink housing and transportation policies to assist individuals with lifelong disabilities in remaining a part of their community. Services to support caregivers and

expansion of in-home adult day care are examples of the creative thinking needed. Wherever possible, segregation of clients with developmental disabilities should be avoided. It is essential that aging and MR/DD systems do whatever can be done to give clients first choice in choosing living arrangements.

Many elderly clients with developmental disabilities live in poverty. Regarding non-clients, we have little knowledge about the economic conditions of the 60 percent of elders with lifelong disabilities presently unserved by the system. Does economic status of clients predict participation? Will these non-clients be forced over time into impoverishment as well? Although "60 percent" is an estimate of the currently unknown and unserved population of elders with developmental disabilities, there is no certainty that such a figure is truly representative of all localities. There is a need for continuing research at all levels.

Setting Our Priorities

Since 1981 progress on developing and implementing solutions to continuing-care problems has been slowed. Appropriations for federally-funded aging-related and long-term care services have been diminished. Even existing services supported under such mechanisms as the Older Americans Act have been cut back, so that operating programs are not available to the numbers of people served previously.

In this atmosphere of diminution, the immediate challenge is to avoid "cannibalizing" each other's program in order to stay alive. Rather, aging and MR/DD leaders must demand resources for their work, as well as support for joint or collaborative programs between them. Pointedly, leaders must avoid "block granting" of programs that puts them in competition with each other, pitting the needs of one constituency against the other.

States run the risk of developing policies and services before there is a clear understanding of the nature of the problem or the characteristics of the population. Long-range planning for this unserved population will not be possible without better information about who they are and what needs they have.

The impact of different service models on various subgroups of the elderly MR/DD population needs to be carefully examined. There are no uniform approaches that will work well with all. Thus, what is needed is a full range of services and better information on how best to match a given individual with a particular mix of services.

One near-term priority for state aging and MR/DD service systems must be to support the expansion of Medicaid home and community care coverage. As mentioned, such coverage is now available on a limited basis in some areas of the country through use of Medicaid waivers. However, Medicaid, as presently designed, still contains a strong institutional bias, forcing individuals into institutional placements that might not be necessary were community-based alternatives available and affordable. Because of Medicaid's severe income restrictions, too many elders are forced into poverty before they are eligible for any publicly supported long-term care.

Several states are experimenting with private insurance options for offsetting some of the costs of long-term care. Most of these policies cover only nursing home care, perpetuating the institutional bias of current federal programs, Medicaid and Medicare. There are now more than 50 private health insurance policies available. Realistically, however, such policies will only be affordable to people in the middle and upper income ranges, and insurance carriers are likely to be unwilling to provide coverage to individuals who are disabled and likely to require long-term care.

A longer-term strategy might include expansion of Medicare to cover community-based long-term care services. Recently, several options have been proposed and examined, such as instituting a "Part C" component to Medicare that would provide insurance against the cost of long-term health care.

It is important to remember that Medicare and Medicaid are health insurance programs. Many elders with developmental disabilities do not have high needs for health care, but rather require social services, such as housing, transportation, and assistance with managing money and other aspects of their lives. As noted, federal funding for social services has been significantly cut back since 1981. An immediate objective for advocates of persons with disabilities should be to support increases in state

and federal funds for social services.

In order to insure continuing, appropriate services for citizens with lifelong disabilities, our ultimate goals should include the development of a national long-term care system that is comprehensive, affordable, and humane. Some advocates have proposed combining state and federal health care and social services programs and funds into a coordinated, single-entry long-term care system in which needy individuals regardless of age or income status have access to basic needed services. Advocates for the aged and for those who have lifelong disabilities should work together toward the realization of this achievable goal.

Recommendations

Adults with developmental disabilities are surviving to later life. In this sense, the aging-related and developmental disabilities "systems" are intersecting; and it is prudent to build bridges between them, bridges that will carry people, ideas, information and assistance across in both directions. For not only is the developmental disabilities system of providers, programs, and services encountering greater numbers of adults with lifelong disabilities, but also the aging network is experiencing and will continue to experience more and more formerly unimpaired adults who suffer later life disabilities. Lessons learned in responding to the needs of elders with lifelong disabilities enrich the capacity to respond to the needs of those with late-onset impairments.

Recommendations from the special interaction at Wingspread have been organized according to the most appropriate organizational level for implementation, i.e., **national or state,** and according to the method or form the recommended action might take, i.e., modification of **public policy, information gathering and sharing, training and education,** and **technical assistance.**

National

A. Public Policy

1. Consideration should be given to the principle of "aging in place," which means keeping older individuals with disabilities in familiar surroundings and altering their current environments, rather than moving them from place to place.

2. There should be federal initiatives to encourage the career preparation and the continuing education of those who will work with the new populations who reach old age. Recruitment, education, and retention of these professional and paraprofessional caregivers must be addressed because of the growing numbers of elders with disabilities.

3. There needs to be a national program of entitlement for long term care.

4. Modification of Medicaid is the logical basis for improving and expanding community-based services to older persons. For example, adult day care could be seen as a generic opportunity providing for all in need, irrespective of their life histories, i.e., lifelong or later life disabilities, thereby offering social and medical services for both relatively functional, mildly impaired DD/MR elders and formerly mainstream elders with later life impairments like Alzheimer's disease.

5. Medicaid rules should be revised to assure that they reflect as much as possible the special services needs of older individuals with lifelong disabilities.

State

A. Public Policy

1. State aging and disability agencies should explore together ways of involving the private sector in coordinated information gathering and sharing, training and education, and technical assistance related to the aging of adults with lifelong disabilities. Joint public-private task forces are one possibility.

2. The diverse service needs of older individuals with lifelong disabilities should be incorporated into the state plans of departments of aging, health, transportation, social services, housing, etc.

B. Information Gathering and Sharing

1. State aging and disabililty agencies need to undertake cooperative introspection, focusing internally within the state to understand and evaluate the total array of existing programs, benefits and services, to identify strengths and weaknesses, and to work for more effective coordination of resources, all of which would result in greater benefits to elderly individuals with disabilities.

2. State agencies need to identify the statutory directives, appropriations, prohibitions, and regulations under which aging or disability programs operate, in order to address misconceptions

3. State aging and disability agencies need to encourage a more intensive program of initiatives aimed at improving services, like living arrangements and transportation, for older Americans with disabilities.

4. There needs to be better understanding of the philosophical, terminological, and operational differences between the aging and developmental disabilities systems. For example, the aging network tends to be oriented toward "settings" (senior center, adult day care program), while the MR system emphasizes "supports" (individual plans, goal plans); "functional skills" means Activities of Daily Living in the aging field, IQ in the MR system.

5. Paralleling a federal initiative, the states need to give attention to the recruitment, education and training, pay, turnover, and licensure of caregiving personnel, from volunteers to professionals. There should be a systematic approach to the education of all service providers, including students in preservice programs, new graduates, and beginning practitioners.

6. State aging and disability agencies should establish interagency task forces as a means of providing better policy articulation and direction for programs and services.

7. Interagency cooperation can be accelerated by considering both individuals' knowledge **and** interpersonal skills in choosing people to serve as liaison between the aging and developmental disabilities systems.

8. Joint, collaborative research and needs assessments conducted by aging and disabilities agencies together will produce more accurate information on the numbers of elders with lifelong disabilities in the state, their characteristics, service needs, involvement in current programs, projected trends, etc.

9. Current information about elders with lifelong disabilities, as well as that subsequently obtained, should be shared regularly with the several information and referral (I & R) services offered by the various community-oriented agencies and departments which operate at state and local levels, e.g., adult services, aging, health, social services, etc.

10. States should consider trying some program initiatives on a demonstration basis, e.g., integrating elders with developmental disabilities into a given senior citizens center, developing emergency foster care within the department of social services for adults with mental retardation, or offering specialized DD/MR day program services to formerly mainstream elders with Alzheimer's disease. Sharing results of these initiatives could ultimately re-shape public policy at state and national levels.

11. State aging and disability agencies should exchange experiences regarding effective public education strategies. Historically, their clienteles have been outside of the social mainstream, have been the subject of misunderstanding and stereotyping. The two systems should work together to overcome these negative attitudes by jointly producing public education brochures, public service announcements, editorials, and other creative mechanisms.

12. State agencies should establish coalitions with advocacy groups, in addition to those representing aging and disabilities concerns, in order to establish or improve service system linkages beneficial to **all** elders with special characteristics. Comprehensive advocacy for better transportation services is an example.

13. State and local aging and developmental disabilities agencies should establish internship exchanges that enable personnel in one system to spend a brief, concentrated period of time at an equivalent position in the other system, so that administrators and service providers, for example, can learn the functioning of the complementary system.

C. Training and Education

1. Attention must be given to dispelling negative attitudes of elderly advocates toward persons with disabilities, negative attitudes of disability advocates toward aging, and the general public's negative attitudes toward aging and disabilities.

2. Statewide conferences focused on the intersections and joint concerns of aging and lifelong disability are needed for personnel in both systems.

3. Cross-training of agency staffs and practitioner networks needs to be incorporated into state training plans for both the state unit on aging and the state unit on developmental disabilities/mental retardation.

4. Training content should be comprehensive,

covering the range of client characteristics, as well as the available human and material resources that can address these characteristics. Participants should become versed in similarities and differences between MR and NR elders, and between DD and non-DD elders. Participants should learn about life transitions, diversities within the populations in question, assessment techniques, funding streams, legislation and other issues related to adults with lifelong disabilities.

5. Staffs and others associated with programs (e.g., elders who are members of senior centers) ought to be invested in the goal of integration if DD elders are to be introduced into aging services or elders with later life disabilities are to participate in DD services. Education should include the goals and philosophy behind integration, and planned mechanisms for discussing problems that may arise, so that integration is seen as a shared priority rather than as an imposition.

D. **Technical Assistance**

1. State aging and disability agencies need to assist each other in establishing joint cooperative standards for services, particularly with respect to adult day care and group homes, to open up more service opportunities for older individuals with lifelong disabilities.

2. Case management operations and methods should be assessed so that a common strategy is employed for determining individual service needs, and there can be cross-referrals between the aging and developmental disabilities systems.

3. Aging and disabilities agencies at both state and local levels should confer with and assist each other in order to develop joint testimony on budgetary needs, joint budget plans, and joint programs of operation.

4. There is a need to rethink housing and transportation policies in order to assist individuals with lifelong disabilities to remain part of their community. For example, the mental retardation system should explore some of the housing options being developed or encouraged by the aging network for elders who cannot remain totally independent any longer, such as accessory apartments, shared housing, ECHO housing, etc.

5. In order to improve communication and cooperation, state aging and disabililties agencies need to initiate an intensive, on-going program of technical assistance to each other. The 1987 reauthorization of the Older Americans Act requires coordination between these entities in planning, information sharing, needs assessments, and service provisions. These should be realized and expanded.

Part one: Introduction

Edward F. Ansello and Thomas Rose

Aging and Lifelong Disabilities: Problems and Prospects

The potential consequences of joint participation by state aging networks and state developmental disabilities systems in addressing the needs of older Americans with lifelong disabilities are exciting, if not tremendous. The considerations and obstacles are many. Tying together two different service delivery systems poses real challenges to and places weighty responsibilities on those agencies that would undertake such a design. Yet the emergence of increasing numbers of elders with lifelong disabilities dictates creative and forward-thinking action.

In structuring new strategies, state leaders will need to direct attention to the intersections of aging and lifelong disabilities. The following is as close to a state-of-the-art review of those intersections as exists in 1988.

Characteristics of Population: A Group of Many Parts

- The life histories of most older Americans with developmental disabilities are generally very different from their non-disabled peers. Most have had little education, have been isolated to a great extent from normal life experiences, and have had few relationships outside their immediate family or disabled peer experiences.
- Dissimilar as they may seem, older citizens with developmental disabilities hold much in common with other members of our aged population as they grow older. They need the same sensitivity to their individuality, the same openness to various solutions for meeting basic human needs. For instance, possible programming options include: (1) traditional settings, such as group homes and sheltered workshops, where one remains with younger developmental disabled adults, (2) integrated generic services for older persons, such as senior centers, adult day care centers, and nutrition programs, (3) specialized services for older persons with developmental disabilities, and (4) active structured retirement. Most older Americans with lifelong disabilities easily adjust to generic senior programs.
- Older citizens with developmental disabilities share many of the same medical conditions and impairments, and have many of the same chronic health problems, as the older American population in general. Cardiovascular conditions top the list, followed by motor, self-care, and other functional impairments.
- Many older persons with developmental disabilities are relatively high functioning, able to communicate, free of maladaptive behaviors, in good health, and do not look disabled. Functional limitations, however, may increase with age, as they do with most older Americans, and they may supersede chronological age as a cause of frailty.
- There is great confusion at all levels over the difference between long-term mental illness and developmental disabilities as both populations age. Older persons with developmental disabilities do have mental health needs which, in many cases, are similar to the American population in general. These needs, however, may be exacerbated with age.
- The stigma of aging and developmental disabilities can be particularly threatening to frail and well elders alike who are anxious about their own cognitive capacities and ability to function competently. It bears repeating that greater variation exists within age groups—disabled and non-disabled—than between them. At the same time, there is some truth to the proposition that some elderly persons with developmental disabilities may be more similar to old-old frail persons (those over age 75) than to the younger aged (those between ages 65 and 75).

• This is a revised version of an essay that originally appeared in **Aging and Developmental Disabilities: Research and Planning. Final Report to the Maryland State Planning Council on Developmental Disabilities** (College Park, Md: National Center on Aging and Disabilities, Center on Aging, the University of Maryland, April 1987).

Aging and Developmental Disabilities: The Silent Emergency

- There is disagreement as to how many citizens with developmental disabilities are aging and elderly. Current estimates range between 200,000 and 500,000. And recent figures suggest that as many as 10 or more of every 1,000 persons over age 60 have a lifelong developmental disability. Based on information available, the population of elders with developmental disabilities may well double in this country before the year 2000.
- Older persons who have a developmental disability are often in double jeopardy and are often not able to advocate for themselves. Their parents or their caregivers—now into their seventies and eighties—historically have served a necessary and very important role as active advocates. For these reasons, attention should be given to the provision of advocacy for this population.
- Two-generation geriatric families are becoming the rule for older persons with lifelong disabilities living at home with their families. Given that these persons are surviving their parents in ever-increasing numbers, the two-generation geriatric family poses a serious challenge to those who share the responsibility for assuring that there is a safety net of basic protection in the community for meeting the health and social support needs of people with disabilities who are elderly.
- At present, only about 40 percent of the estimated 200,000 to 500,000 older Americans with lifelong disabilities are currently known to the MR/DD service network, with an even smaller percentage actually being served. Long-range planning for this unserved population will not be possible without better information about who they are and what needs they have.
- For the population of older persons with developmental disabilities, current programs, services, and funding sources are incremental, fragmented, categorical and confusing. There is a need to stimulate high quality, coordinated, collaborative, and integrative program development.
- If people with lifelong disabilities who are elderly are incorrectly perceived to have a support network already in place within institutional or community systems, some may interpret this as evidence that this population is being adequately served. Without accurate statistics about community supports, further planning and program implementation attempts will be futile.
- In this context, the perception of the problem is a crucial problem itself. Certain professionals in both the aging network and the MR/DD system refrain from becoming involved in addressing the needs of older persons with developmental disabilities because they overestimate the difficulties of effecting improvement in existing programs. To bring about change we must first increase our knowledge of aging and lifelong disabilities and develop the skills to translate this knowledge into effective service.

Maintaining Relatedness: The Need for Choices

- Far too many older persons with disabilities live in institutions today. Emphasis should be placed on alternatives to institutionalization and policies that promote stability and permanence in the community.
- The more restrictive settings encourage less adaptive skills and greater dependency. Various less restrictive supportive service alternatives and opportunities in the community need to be explored in place of institutionalization.
- Community living options for this population include home care, foster/personal/family care, group homes, supervised apartments, shared housing, boarding homes, sheltered housing, and nursing homes. These options can be provided through either the MR/DD service system or the aging network, or through a combined network.
- Community living promotes independence, health, skill maintenance and development, positive peer relationships, and access to generic programs and services. In most, if not all, cases the mobilization of community-based resources not only adds to the general quality of life of older

people with disabilities, but also assists in promoting skills of positive adaptive behavior.

- Structured living arrangements which encourage the development of informal support networks and the use of community health and social services—thus allowing for continued independent living—have not adequately been explored for older persons with developmental disabilities.
- Financial and permanency planning today and for the future should become the rule for older persons with lifelong disabilities living at home with their families. In the midst of crisis, when their parents die or can no longer care for them, institutionalization may be seen as the only viable alternative.
- The number of older people with disabilities on residential and day waiting lists, and the time they remain on waiting lists, must be examined. Institutional placement is **not** the only alternative, even in the midst of crisis.
- Various models of community-based respite care, including adult day care, should be explored to support the families of the developmentally disabled who are themselves growing older.
- It is important to encourage the continued development of community activities so that elders with developmental disabilities can have the option to choose active retirement if they so wish.
- Again, most older persons with developmental disabilities now living in institutions do not need to remain there. Institutional life has created a complex set of problems. The task of deinstitutionalization is enormous, and the solution should not simply be the uniform and often inappropriate transfer of former residents of institutions to nursing homes.
- State and national leaders in the aging and developmental disabilities networks, in cooperation with local leaders, must consciously and creatively work together to provide the leadership necessary to ensure that the nation's public and private resources are marshalled to address the needs of older Americans with lifelong disabilities.

Edward F. Ansello

The Aging and Disabilities Partnership

The Wingspread Conference is the culmination of efforts that began in 1985. It is also, we hope, the beginning of efforts that will grow in each of the states over the next several years. A culmination and a beginning...

At that time, Dr. Thomas Rose and I began what became a collaboration in aging and disabilities—he as an active member of the Maryland Developmental Disabilities Council and coordintor of the aging and disability program at Montgomery College—I as a gerontologist and a director of the Center on Aging at The University of Maryland. We realized that our disciplines increasingly were intersecting.

The demographic revolution of the twentieth century has meant not only that mainstream adults are living longer in unprecedented numbers, but also that special populations are surviving in ways not previously experienced and, importantly, not planned for. Adults with developmental disabilities are outliving their parents who may have kept them out of the MR/DD service system, or are aging along with their parents in two-generation geriatric families. These families, in turn, pose new and special challenges.

In order to research the needs of these populations, to develop policy, to plan and to manage programs and opportunities, professionals in the two systems of developmental disabilities and aging must work together. Yet our two systems often speak different languages and operate under different philosophies, laws and regulations. We have seldom interacted with each other. There is precious little history of cooperation. We are painfully aware of the differences and the barriers between us. On the other hand, our two systems are being drawn together by the evolving status of our clientele. We can and must learn to read the differences between our two systems as opportunities, not obstacles—as complement, not challenge, to our own expertise. We must begin to interact more meaningfully.

We conceived of the Wingspread Conference as an opportunity: an opportunity for the leaders of the two systems from the several states to share research, to understand best practices involving elders with lifelong disabilities, to become better acquainted with the complementary service system, and to initiate or advance action plans for this population.

We know that this Conference is a significant point in the work of The University of Maryland Center on Aging, and we hope that the ideas, togetherness, and dialogue which come forth will lead to actions that benefit our nation's elderly with lifelong disabilities.

Older Americans with Lifelong Disabilities: Images of Potentiality

The life histories of aging and elderly Americans with lifelong disabilities are, for the most part, very different from the older American population in general. Here are five stories which illustrate the unique life experience and potentiality of older persons who have endured lifelong disabilities:

- **John P., age 65, is mentally retarded with a speech impairment. He dropped out of grade school, and he cannot read or write. He has been employed as a ranch hand, a delivery truck loader, and a custodian. He is divorced with three children. Now retired, John works part-time as a custodian in the apartment building where he rents an apartment. He has a history of heart problems. His quick temper can be soothed when clear explanations and understanding are provided.**

  John has had many difficulties with family members throughout his life. His mother is deceased; the whereabouts of his father are unknown. His former wife is a sore subject for John, and his two sons have caused him serious problems through verbal and physical quarrels. In addition, John's brother-in-law severely assaulted him years ago, which caused more brain damage. John now resides alone, and spends a great deal of time with a much younger woman friend who is also disabled.

They enjoy going out together, and lead socially active and independent lives.

■ Jane B., age 78, is developmentally disabled. As a child Jane was placed by her mother in an institution for mentally retarded persons. She lived there until age 30. Jane stated that she would have been released earlier, but was not as there was no place, nor anyone responsible, willing to take her in. Upon leaving the institution, Jane moved to the private home of a doctor where she was employed as a housekeeper. Jane is fortunate to have cultivated the friendship of the physician's granddaughter who is 15 years her junior, and who has taken a personal interest in her.

Jane now resides in a group home for adults with developmental disabilities. She is visited by her longstanding friend who advises her on personal matters and serves as Jane's legal guardian, taking care of her financial affairs. Jane shows an interest in meeting people, but it is difficult at times for her to interact with positive outcomes. Other than her guardian, she has not had much opportunity for building a socially cohesive network of friendship. Jane spends her time sewing, cleaning, growing houseplants, observing others' activities, and visiting the community senior center.

■ Harriet C., age 65, was institutionalized at an early age, and has had no contact with her parents or other family members. At age 35, Harriet went to live with a family where she worked as a mother's helper. In 1980, she moved to a special apartment building for adults with disabilities. An Independent Living Counselor visits Harriet weekly to assist her with money management and decision-making skills. Harriet lives with a man much younger than she. She volunteers several days a week at a senior center, and actively participates in a recreation program for adults with disabilities. She takes pride in her well-groomed appearance, and enjoys visiting her neighbors to lend advice and a helping hand.

■ Susie J. is 67 years old and developmentally disabled. The eldest of three children, Susie's father died when she was in her teens. Her sister, who is mildly mentally retarded, was placed in an institution at that time. Susie quit school to help support the family. When her mother died she continued to work and to support herself. She maintained regular contact with her sister. In 1979 Susie's sister was deinstitutionalized and came to live with her. Susie is now retired. Active in recreational programs for adults with disabilities, she has won awards for her handmade crafts. Susie often invites neighbors who have no family to her home for holiday meals.

■ Alice W., age 62, is mildly mentally retarded. She is able and zealous to lead an independent life. Alice dropped out of the 6th/7th grade upon the advice of school officials, still unable to read. She can, however, sign her name and tell time. Alice lived with her parents until their death. She now lives independently in her own apartment. Her aunt assists her with money management.

Throughout her adult life Alice has been a humanitarian worker. She cared for her aged parents and worked to help others who needed care assistance. Her first job was in a sheltered workshop where she was trained in lawn and garden maintenance. She also was trained as a nurse's aide, but she never had the opportunity to practice her skill outside a sheltered setting. Now retired, Alice spends her time keeping her apartment immaculate and following her religious beliefs.

Jean K. Elder

On Aging and Lifelong Disabilities: A New Response

FOREWORD

In this discussion of the intersections of aging and lifelong disabilities, Dr. Elder states that stereotypes about persons with developmental disabilities must be overcome as a prerequisite to changing public policy. One myth, explains Elder, is that the elderly and people with disabilities are helpless and dependent. A very general model of productive volunteerism is set forth, followed by a review of federal initiatives to support family caregivers, in which attention is focused on reducing the need for formal services and institutional care. From 1982 to 1986, Dr. Elder was commissioner on developmental disabilities, U.S. Department of Health and Human Services. In 1986, she was named acting assistant secretary for human development services. Dr. Elder has written numerous articles on developmental disabilities.

Much has been said about the "graying of America." And much has been said about the "silent minority"—a minority not so silent anymore. Not only are the disabled not so silent themselves, neither are their families.

Yet many stereotypes still must be overcome as a prerequisite to changing public policy. Among the stereotypes about the aged and disabled are those of helplessness and dependency. Many of the programs for both populations, bound by tradition and bureaucratic resistance, and usually with the best of intentions, encourage dependency.

We know the facts to be otherwise. Most older Americans are keen of mind and healthy of body well into their later years. And most people with disabilities are not incapable, but definitely capable of productivity, self-sufficiency, and integration into the mainstream community.

That is why the agenda of this meeting is so challenging: to look past the stereotypes about aging and disabilities so we may create an agenda for the next century for that segment of the population which is both aging and disabled.

Productive Volunteerism

The Administration on Aging and the Administration on Developmental Disabilities jointly funded last year a model demonstration project, Enhancing the Life Changes and Social Support Networks of Elderly Disabled Persons, directed by Phyllis Kultgen. One significant component of this project was its matching of elderly persons with developmental disabilities with volunteer peer companions at nursing homes and Older Americans Act-funded senior citizen centers. An anticipated outcome of this effort was an enhanced quality of life for the elders with developmental disabilities.

Volunteer companions came away from this experience with a much more positive perception of the person with whom they interacted directly. It may be concluded that interaction among disabled and non-disabled elders leads to the overall enhancement of the social status of persons with developmental disabilities. Concomitantly, volunteers from nursing homes and senior centers expressed genuine satisfaction with developing friendships with disabled persons. It could be argued that their own social status and self-esteem were enhanced by their interaction with persons with developmental disabilities.

Support for Family Caregivers

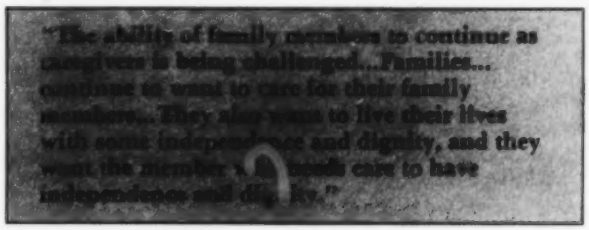
I am working very hard on an initiative that I refer to as the Family Caregiving Project. This is a department-wide initiative to support caregivers in their efforts to (1) prevent inappropriate institutionalization of a family member, (2) prevent unnecessary hospitalization and reduce the length of stay for a family member, and (3) remain employed, rather than quitting to provide care at home.

Family members—wives, husbands, daughters, sons, friends, neighbors—provide the great majority of help needed by individuals to continue living in their own homes and communities. There are approximately five million older Americans living in their communities in the United States who need assistance of another person or a special aid to perform one or more selected personal care activities.

Editor's Note: This is an abbreviated version of Dr. Elder's opening Conference address.

And about 80 percent of the care provided older people is by family members, friends, and volunteers.

Ninety percent of the nearly four million people with developmental disabilities also live at home with their families. And many more of the estimated 29 million Americans who are suffering from mental illness are remaining in their own homes and communities than ever was true in the past.


"The ability of family members to continue as
caregivers is being challenged...Families...
continue to want to care for their family
members... They also want to live their lives
with some independence and dignity, and they
want the member who needs care to have
independence and dignity."

Obviously, as we look at what is happening in our culture, the ability of family members to continue as caregivers is being challenged, not only by the sheer volume of the need, but also by the changing demographics of the work force. Women, the traditional caregivers, are now working outside the home. It is very clear to all of us as we struggle with these policy issues that families, regardless of these changes, continue to want to care for their family members. When you visit with them and talk with them, you will hear from them that they also want to live their lives with some independence and dignity, and they want the member who needs care to have independence and dignity. Those are phenomenal challenges for us.

The private sector is committed to caregiving and is seeking assistance. We have to think creatively about how to work best with them and lead our expertise to them so that they can get involved in a very positive way. It is clear to me that they are looking for ways to assist their employees with the care of their family members.

I think it is essential that the Department of Labor be involved in this Family Caregiving Initiative, as should ACTION, the Veterans Administration, and the Department of Agriculture. I want to make this as broad as it possibly can be.

Last year, our department sponsored a conference on Supporting Family Caregivers, attended by some 30 people representing a variety of agencies within HHS, as well as three private foundations, eight national professional and voluntary associations, and a host of other interested organizations and individuals. We asked participants in that conference to join together in a common pledge to begin to share information and to provide better training for professionals, para-professionals, and volunteers who work with caregiving families. We are working very hard to turn those pledges into reality.

In Conclusion

We have seen a very different view of people with developmental disabilities in the last decade, and especially since we began the employment initiative four years ago. We have changed the thrust of the developmental disabilities program from one that catered to and even encouraged dependency into one which emphasizes self-sufficiency. As assistant secretary, I encourage those same goals in our older Americans program to seek outcomes—including productive volunteerism in the community, continued participation to the extent desirable and feasible in the economy, and independent living arrangements, rather than in senior citizen residences or institutions.

The Administration is already deeply involved in 12 projects for serving persons with Alzheimer's disease, aimed at providing support for efforts to find new and innovative ways to enhance the abilities of informal caregivers to serve vulnerable older persons at home and in the community so as to reduce the need for formal services and institutional care. Four other projects seek to improve the quality of home care through demonstrations and training for home health aides and their supervisors. To me, the family caregiving approach has enormous potential.

Jack Ossofsky

The Aging Developmentally Disabled as a Dimension of All Our Goals

FOREWORD

Jack Ossofsky in describing the capacities and potential contributions of the aging network for serving mature adult persons with lifelong disabilities calls for a nationwide "investment in sensitivity training and education for both networks." Citing areas of needed action, Ossofsky concludes that a first order of priority must be to articulate a national policy based on "a return to the fundamentals and directions of building a caring society." This lucid discussion of the partnership between aging and lifelong disability does much toward clarifying some of the complex issues involved. Mr. Ossofsky, who is president of The National Council on the Aging, Inc., is one of the nation's leading advocates of the aging.

The planners of the Conference call for a partnership for the twenty-first century. It gives us less time than it would appear. By then the demographic data and those people who will then have insinuated themselves into our agendas whether we are ready or not. We are, therefore, urged to start getting ready now. Even now there are more older people in our midst and in the cohorts ready to march into our programs than we are able to serve. And within their ranks, also aging in increasing numbers, are the old who have carried lifelong disabilities with them.

Successes of Past and Current Efforts

The partnership between aging and lifelong disability is possible and real, and its precursors are already here in a number of different related areas. Some, the National Council on the Aging and I have been closely associated with.

As one who has been involved particularly in highlighting the capacities and potential contributions of the aging, I see the evidence of such a partnership in the Foster Grandparent Program which we designed during my first year at NCOA, and in the more recent Family Friends Program which NCOA launched three years ago in Washington, and which we are now replicating in nine cities across the country.

Building on the Foster Grandparent concept, Family Friends recruits and trains older volunteers to work in homes of families with chronically ill and developmentally disabled children. They provide training, recreation, and friendship to these children—and comfort, friendship, and linkage to community resources for the parents. The Family Friends model will surely be further replicated with older home aides and paid older people and soon become a widespread, well-known modality of service.

Moderately disabled young adults, including some with developmental disabilities, are now being counseled by older volunteers in Project Teamwork. This is a new endeavor in which NCOA is working with the Foundation for Exceptional Children to open the job market for disabled young adults, help them find jobs and coaches, and support them as they learn work skills and the requirements of the work place.

In addition to the use of older volunteers and paid workers, the "aging establishment" (and the word connotes more cohesiveness than is merited) also has facilities and programs that are opening up to the challenge of serving those with lifelong disabilities. Those services are there to serve all the aged regardless of prior circumstances. The aging developmentally disabled and the aging parents of mature adult disabled persons are part of the "aging," and are entitled by right and by law to share in these programs.

The senior center movement, the burgeoning adult day care centers, congregate meals programs, transportation services, and other elements of the community-based continuum of aging services are beginning to show that those with developmental disabilities can be integrated and served. NCOA is currently launching two demonstration projects using senior centers as after school facilities for latch key kids, and if this experiment proves workable, we hope it can be expanded to test the potential role of the [senior] center for intergenerational programming with developmentally disabled children, for socializing for children, for respite for their parents, and for sharing and giving by the senior center members. A key element in this project, in addition to the facility itself, of course, is the

involvement of the older [senior] center participants.

But the center itself, as a facility for socializing, recreation, social service support, health promotion, and more, needs to, and in some instances already does, reach out to and serve the frail aged, including those with lifelong disabilities. NCOA's study of **The Senior Center and the At Risk Aged**, with its resulting guidelines to center leadership and the involvement of the organizations of the disabled, highlighted these issues. It was followed up with the implementation of training for staff of aging programs across the country.

A recent newsletter survey of the members of the National Institute of Adult Day Care served to sensitize day care providers to their potential for serving not only the emotionally frail and those with symptoms of dementia, but also those with mental retardation and other lifelong developmental disabilities. [It] documented the beginnings of such service being extended to new segments of the vulnerable aged and, most important of all, helped sensitize the adult day care network to a new potential of clientele.

Clearly, at the state level, we can also cite increasing instances where the offices of aging and departments dealing with developmental disabilities are beginning to plan together, to explore overlap of constituencies and needs, to see the ramifications of the creative use of Medicaid waivers for the developmentally disabled and the otherwise vulnerable aged, and to test other partnerships as well. In a time of increasing demand and limited resources, cross-funding of services, outreach and training and shared efforts, and coordination between the aging and DD networks could stretch resources and help overcome the real issues of turf, conflicting eligibility regulations, and different program emphases.

"In a time of increasing demand and limited resources, cross-funding of services, outreach and training and shared efforts, and coordination between the aging and DD networks could stretch resources and help overcome the real issues of turf, conflicting eligibility regulations, and different program emphases."

Future Outlook

As we in the field of aging learn more about the DD networks and their assets and, more importantly, about the developmentally disabled themselves, I believe we will find more benefits to the partnership whose foundation we lay today and ways to use it more effectively.

As we learn more about the capabilities of many of the developmentally disabled themselves, and increase our comfort in dealing with them as persons, not conditions, we will, I believe, find that **they** are an asset too in our attempts to find new resources for service to the aged.

We in aging services need to learn more from the experiences of those who serve the mentally retarded and developmentally disabled, not only as we serve more of "your" traditional clients who have grown old, but also as those who age in place in "our" programs increasingly show signs of emotional and mental programs, including dementias. We need to learn more from you about your significant success in demonstrating the effective use of Medicaid waivers for alternative services in small group homes to the previously or potentially institutionalized. These demonstrations hold great promise for all the frail aged if the waivers road block can be opened.

We speak of the "network," but it is a mix of services and resources, promises and hopes, gaps and fragmentation. What saves it is that most older people manage fairly well without it, living their lives in families and in communities. It is when time erodes their resources, families, health, and capabilities, as it too often does in late life, that they seek to utilize the "network," and having been strangers from it, have difficulty finding what they need in the place and way they would like to have it. Except for the senior center which emphasizes services to the well aged and often has a positive community image, the aged who are well use the service network only little and have trouble getting hold of it when they need it most.

Funding has not kept up with the numbers nor the needs, and the Congress has heaped new "must do's" on the key service legislation without adding adequate "with what's."

As one who is no stranger to the developmental disabilities service network, for my grandson has Down syndrome, I know that the network is no less

fragmented, hard to reach, and uneven in the quality of its services. In some respects, it has even softer data about potential participants in our joint programs. As [those who were kept at home in an earlier period] grow up and grow old, and especially as their parents age, they enter the search for supports and services, often for the first time. Both our networks must develop a joint agenda which finds ways to make our public and voluntary agency services more accessible.

Both our networks tend to deal with people **in extremis.** This was to have been avoided in the Older Americans Act with its emphasis on expanding opportunities, health promotion, employment, and support for the preventive gerontology aspects of community services and service centers, in addition to its requirements of service to the frail and most vulnerable. But the recent pressure of penurious policy and the lack of an alternative long-term health care system pushes it and its state and local agencies to filling gaps in community-based care and skewing its resources toward health-related social care.

Commitment to Family Caregivers

In recent years, as the pressures of deinstitutionalization and dehospitalization put increasing burdens on the families of the sick and disabled, both our networks have begun to look at the support and the care of the caregiver. The aging of the population has, for most older persons, meant caregiving by upper middle-aged and young-old women. In the case of the developmentally disabled who are themselves growing older, the caregiver is often an increasingly frail aged person coping with her own or his own aging along with that of an older adult child.

The circumstances of the second group of caregivers is complicated by the need to plan for stable, secure, permanent residence and care for the dependent adult child in the anticipation of the caregiver's frailty or death. For many of these parents, the need to ask for sheltered living arrangements or protective services often carries with it an old stigma from a prior time from which they sought to hide. For some, seeking such help from agencies serving the aging may, indeed, make it easier to accept assistance and services. Aging organizations which offer retirement preparation materials need to explore the preparation of special modules for this segment of the aged.

Our partnership must seek to support and serve the caregivers of both segments of the population we serve. They need to be made part of the emerging organizations of community-based caregivers, self-help and supports groups. Corporations, churches, unions, adult day care, family service agencies, and other groups are beginning to sponsor and provide support, training, respite, and help to caregivers. These efforts merit—require—our support, participation, and involvement as well.

It cannot be lost on us either that the feminization of caregiving and feminization of aging both lead to the increased feminization of poverty in our society. Caregivers belong on our agenda.

Hope and Frustration

I will stop here to tell you a story. I had occasion to be hospitalized briefly, unexpectedly. As they wheeled me into a room, [I observed] that my roommate had Down's syndrome, and he was an adult. I had scarcely been moved into my bed when his father came rushing to my side of the bed to prepare me for what I might find an uncomfortable situation. He immediately said to me, "I hope you don't mind, My son is disabled. I am sure he won't be any trouble to you." I said, "It will be all right." Having recognized what I knew well from my own family experiences, I tried to assure him that there was nothing to worry about.

The time I spent in that room with that man was in no way different than it might have been with any other patient who had his problems. I had mine. Each time his father, who was well into his seventies, came in, he was loving, he hugged him, he kissed him, he talked with him, and he came several times a day. And he always came to intercede, concerned about that son.

As I was being discharged, he came over and again was apologetic. And I tried to reassure him by saying, "I understand. There's nothing for you to be concerned about, however. He's fine. He talked. He took care of his needs...I have a Down's syndrome grandchild. I understand your concern, but you don't have to be worried about him. He's doing very well."

And tears welled up in his eyes. And seventy years

of concern, of caregiving, of the pressures he carried suddenly came forward, and he began to ask questions about my grandson: who is doing well, who is in school, who is being mainstreamed, who just starred as the boy in **Peter and the Wolf**, who sang in his church choir...And this man said, "Oh, if only that had been possible for my son. When he was born, they told me I would have to put him in an institution. I visited the institution, and I ran from it and never wanted to go back. How marvelous that years later your little boy can get on a school bus with other children and go to school."

What that man felt, and what he carries with him in his older years requires not only that we build more sheltered workshops where his son goes, and not only more facilities for housing where his son lives now with other people like himself and has begun to function in the community, but that we don't forget that father either. That is part of our constituency—our constituencies. We need to assure this man, as his life ebbs, that the services, the outreach, the comfort, and the sense of security will continue for his son's life. So we do, indeed, have a joint mission. And you may understand why I have a commitment to our joint cause.

The Policy Challenge

In seeking to build a working partnership, we need to confront and explore a number of issues.

Having shaped bureaucracies to dispense service and dollars, we are too often focused on how we use existing mechanisms, rather than what the person wants and needs. We must serve each person one by one and find ways to emphasize the being that remains under the frailty and seek his or her enhancement and emergence. The person is not the disease or frailty. The disease or frailty is not the person. We must seek to keep our programs people-centered, even when that makes administration more complex. The commonality of chronology must not be permitted to blind us to the individuality of each person who comes to us or whom we find.

"We must serve each person one by one and find ways to emphasize the being that remains under the frailty and seek his or her enhancement and emergence. The person is not the disease or frailty. The disease or frailty is not the person."

Our partnership requires unity before we have a unified agenda. Turf and resource struggles stemming from competition for a piece of the diminished pie is a disservice to our high purposes, but remains a reality as long as resources are inadequate. We must strengthen one another's voice and present a chorus of joint demands to the public, to the legislators, and to the administration at all levels. Let us not cannibalize each other's programs, but demand sufficient resources for both and for special joint programs.

Aging organizations bring to this partnership a somewhat different perspective based on a different background. Advocates for the disabled have sought more access to the mainstream programs. Aging advocates have, by and large, succeeded by creating categorical programs. Our experience teaches us that the aged, and probably the lifelong disabled, lost out in the past when broad programs without clear directives regarding target populations were enacted. Without losing our identity, we can support each other's categorical program efforts and build something more for both.

We should insist on the need for an an investment in sensitivity training and education for both networks. Those dealing with the aged are often unfamiliar with the conditions involved in developmental disabilities, reluctant to work with the retarded, unsure of their skills, and unfamiliar with the people involved. It is probably the same for those fearful of dealing with aging and, in the process, confronting the reality of their own aging and their mortality. Additionally, the aged, fearful of their own increasing frailty, are often reluctant to add to their milieu those whose disabilities or mental faculties mirror precisely what the aged are fearful of having happen to them.

None of this is to suggest tht we should not proceed. It is, rather, to emphasize that we must anticipate behavior, prepare for it, avoid it through training in sensitive action. Where this has been done in senior centers and adult day care or in communal housing facilities, it has worked well, and the

expected mutual supports and symbiosis developed. It takes investment and it takes new resources.

Our partnership needs to reach into the community, too, to gain community support and, especially, more opportunities for employment for our target groups. Discrimination in the work place stands in the way of economic security and income protection for both our constituencies. [NCOA has] developed a tool to overcome it (called GULHEMP). Let's use it and other approaches to insist on job training and placement for all who **can** work, who **want** to work, with an emphasis on their capabilities, not their limitations.

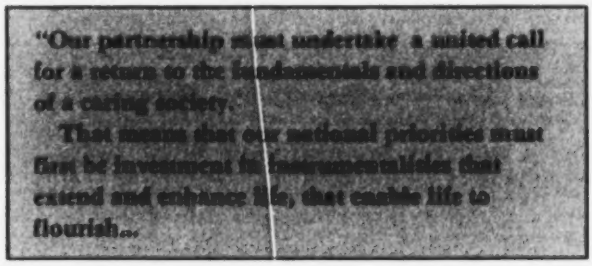
The decline of the labor force between now and the twenty-first century provides us with an opportunity to respond affirmatively with trained, properly placed workers. This means we have to be prepared to encourage those who have been previously rejected or never exposed to the world of work to leave the shelter of our programs while we support them in the period of transition. Training, placement, screening, advocacy all take funds. But our joint emphasis on hiring capacity and readying the workers and the job market would pay back society many-fold of its investment.

Many of those we seek to serve, however, cannot enter the work force. Poverty is an added portion to their cups. Our partnership needs to give priority to ending poverty among the most vulnerable who make up a significant portion of the SSI beneficiaries. That federal-state floor of benefits does not yet equal our own public definition of poverty, and few states supplement it so that it comes anywhere close. If we are to end the perpetuation of poverty, let us speak with one voice to demand that SSI benefits at least equal, if not exceed, the poverty mark which our communities have established.

Concluding Observations

It is not enough for us to manipulate systems and to tinker with programs. We must look at the policy context and the larger issues within which we operate and which affect our vulnerable constituencies.

Most of the programs and systems we represent grew from a period when the nation's leadership at the highest levels called for a commitment to the poor and the vulnerable as the highest national priority. Our partnership must undertake a united call for a return to the fundamentals and directions of building a caring society.


"Our partnership must undertake a united call for a return to the fundamentals and directions of a caring society.
That means that our national priorities must first be investment in instrumentalities that extend and enhance life, that enable life to flourish...

That means that our national priorities must first be investment in instrumentalities that extend and enhance life, that enable life to flourish, not endless investments in instruments of death and destruction.

No, we have other priorities represented in the lives of people who need escape from nursing homes and institutions, but for whom there is no adequate community-based system of quality health and social care.

No, we represent people who need a comprehensive long-term care health system that protects from the catastrophy of a long illness, a chronic condition, or a lifelong disability. How long can we expect individuals and families to carry alone the endless cost and unending burdens of long-term care?

No, we represent people tied to their present environment by the unyielding policy that limits medical waivers which could permit greater experimentation with new modalities of service, home health, day care, and small group residences for the aged and disabled.

No, we represent people whose lives have been limited too long by the medicalization of their options, who need an integrated system of health and social services based on a consumer sensitive and responsive program where resources for non-medical services are not controlled by the Rx of physicians, where competent social workers, therapists and, indeed, family members are capable of making decisions and providing care, and where reimbursement does not require a medical degree, and where the voice of **the person** is heard in the land.

No, we represent the concerns of those often not able to express their needs as well as those who can,

but are overlooked as yesterday's people. And we need to remind policy-makers of both parties and in all places of power that the social insurance mechanism which enabled us to provide much in benefits and protection has not yet been so effective that we can take back with one hand what improvements we provide with another, and that the time has come to use that well-accepted, universal entitlement system to fund a national care program without the stigmas of means tests or the threat of pauperization, but with the promise of accessible, integrated health and social services for all.

We can build a partnership on program and service goals, but it must be based on a vision for our communities and our nation that takes us into the twenty-first century committed to the human betterment of the frailest, the weakest, the least aware, so that we can all reach the full potential of our years and our being.

Part two: Building Partnerships

Marsha Mailick Seltzer

Introduction to Aging and Lifelong Disabilities Context for Decision-Making

FOREWORD

The population of Americans with disabilities who are elderly is a very difficult one to define precisely. This is because both delimiting characteristics—"aging" and "lifelong disabilities"—are themselves elusive concepts. The author's purpose here is to clarify the essential facts now known about aging and lifelong disabilities, the variable characteristics of this population, and the service sectors currently being utilized. Dr. Seltzer is associate professor of social work at Boston University where she has done extensive research in mental retardation and aging.

What is a developmental disability? The current definition of a developmental disability, adopted in 1978[1], is as follows:

> The term developmental disability means a severe chronic disability of a person which—
>
> (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
>
> (B) is manifested before the person attains age 22;
>
> (C) is likely to continue indefinitely;
>
> (D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic sufficiency; and
>
> (E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

The largest subgroup of the DD population consists of persons with mental retardation. Mental retardation is defined as significantly subaverage general intellectual functioning (IQ of approximately 70 or below) existing concurrently with deficits in adaptive behavior and manifested during the developmental period (between birth and the eighteenth birthday).[2]

In order for MR to be a **lifelong** handicap, it must not only be manifested before the twenty-second birthday, but it must also continue to be manifested through adulthood. Research on the prevalence of mental retardation reveals that it is a dynamic rather than a static condition. During school years, approximately 3 percent of the school age population is classified as mentally retarded, while in adulthood the prevalence rate drops to 1 percent. This drop occurs because there is less "official scrutiny" of intellectual functioning in adulthood than during school years, when the educational system is the primary diagnostician.

In old age, at least two phenomena affect the prevalence of MR. First, some segments of the MR population, such as those with Down's syndrome, have a shorter lifespan than the general population. This has had the effect of reducing the number of MR persons who survive to old age. Second, some persons who were identified as mentally retarded in childhood, but whose functional skills were adequate enough to avoid this label in adulthood, may re-enter the MR service system in old age when they become more frail and once again in need of formal services. This phenomenon **increases** the number of known MR persons in old age. The net effect of these two phenomena has not yet been precisely estimated.

Demographically, age is often defined in years. Common ages used to demarcate the onset of old age in the general population include 60, 62, 65[3]. Some gerontologists differentiate the "young-old" and the

Editor's Note: Dr. Seltzer's paper reflects her extensive experience with the population of elders with mental retardation; generally, this is the only diagnostic subgroup of the elderly population with developmental disabilities about which much is known.

[1]P.L. 95-602, Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978.
[2]H. Grossman, ed., **Manual on Terminology and Classification in Mental Retardation** (Washington, D.C.: American Association on Mental Deficiency, 1983).
[3]J.S. Siegel, "On the Demography of Aging," **Demography** 17 (1980): 245-364.

"old-old," using 75 or 80 as the cut-off point between these two groups.[4]

Other gerontologists have offered alternative models for the definition of aging and old age. For example, Eisdorfer's functional definition identifies four stages of life: (1) **children and youth** in whom society invests resources in anticipation of future benefit, (2) **adult workers** (paid and unpaid) who generate the goods and services used by the entire society, (3) **healthy persons who have retired** from their ordinary employment, but who are not functionally dependent upon others, and (4) **frail individuals** who cannot function independently. It is only those in group four who are considered to be elderly, irrespective of age.[5]

Yet another approach to the definition of aging was summarized by Birren who conceptualized three components of aging: (1) **biological aging,** which is an individual's capacity for survival, (2) **psychological aging,** which is a function of changes in a person's "adaptive capacities," and (3) **social aging,** which is the extent to which an individual fulfills the expected social and cultural roles.[6]

In research on the MR/DD population, the term "elderly" generally has been defined demographically (age in years)...Various ages have been used as the lower limit of old age, the most common of which is age 55.[7] Some policy-makers have argued for the use of age sixty as the defining lower limit for the MR/DD population in order to conform with the Older Americans Act.[8] Disagreement still remains about this issue among policy-makers, planners, and researchers. Therefore, the definition of the lower age limit of this stage of life for the MR/DD population remains an open issue—one in need of our attention at the present time.

Size of the Population

If we focus only on the MR subset of the DD population for the moment, use age 55 as the cut-off point, and use a 1 percent prevalence rate for mental retardation, it can be estimated on the basis of Census data that there were approximately half a million mentally retarded persons aged 55 and over in the U.S. in the year 1982.[9] However, only about 200,000 persons are currently recipients of services from the MR/DD service system.[10] Thus, only about 40 percent of the expected number of elderly mentally retarded persons are currently known to the MR service network.

While some individuals in the unknown group may be receiving services from the network of generic aging services, we have very little information about how widespread this phenomenon really is. Obviously more accurate epidemiological studies are needed to provide better estimates of the size of the elderly MR population and to determine whether the 1 percent prevalence estimate is the most valid estimate on which we should base our planning efforts.

Variability of Population

Gerontologists often note that as any cohort of the population ages, it becomes more heterogeneous due to the impact of differential social, psychological, and health-related experiences. This phenomenon appears to be true with respect to the MR/DD elderly population. [As] Janicki and Jacobson noted..."greater variation in group and individual skill levels occurs with advancing age and...impairments of aging impact unevenly upon different individuals."[11] [The point is] that a range of needs—and a continually changing range at that—

[4]See, for example, G. Streib, "The Frail Elderly: Research Dilemmas and Research Opportunities," **The Gerontologist** 23 (1983): 40-44.
[5]C. Eisdorfer, "Conceptual Models of Aging: The Challenge of a New Frontier," **American Psychologist** 38 (1983): 197-202.
[6]J.E. Birren, "Principles of Research on Aging," in **Handbook of Aging in the Individual,** edited by J.E. Birren (Chicago: The University of Chicago Press, 1959): 3-42.
[7]M.M. Seltzer and M.W. Krauss, **Aging and Mental Retardation: Extending the Continuum** (Washington, D.C.: American Association on Mental Deficiency, 1987).
[8]M.P. Janicki, L. Ackerman, and J.W. Jacobson, "State Developmental Disabilities Aging Plans and Planning for an Older Developmentally Disabled Population," **Mental Retardation** 23 (1985): 297-301.
[9]M.W. Krauss, "Long Term Care Issues for Mentally Retarded Elders," paper delivered at the 111th Annual Conference of the American Association on Mental Deficiency, Los Angeles, 1987.
[10]M.P. Janicki, L.A. Knox, and J.W. Jacobson, "Planning for an Older Developmentally Disabled Population," in **Aging and Developmental Disabilities: Issues and Approaches,** edited by M.P. Janicki and H.M. Wisniewski (Baltimore: Paul H. Brooks, 1985).
[11]M.P. Janicki and J.W. Jacobson, "Generational Trends in Sensory, Physical, and Behavioral Abilities among Older Mentally Retarded Persons," **American Journal of Mental Deficiency** 90 (1986): 496.

must be addressed by the service delivery system in order for it to be responsive to the lifelong characteristics of this population.

Service Sectors Utilized

Broadly speaking there are three service sectors that are now utilized by elderly MR/DD persons. These are:

The Age-Integrated MR/DD Service Sector. Nationally it is very common for elderly MR/DD persons to be served in age-integrated programs [such as group homes and sheltered workshops]. According to research conducted at the University of Minnesota Center for Residential and Community Services, in 1982 fully 25 percent of all mentally retarded persons served in community residences were between the ages of 40 and 62, and another 5 percent were aged 63 or older.

How different are elderly and younger adult MR/DD persons in their characteristics and service needs? Elderly MR/DD persons, like all of us, experience age-related declines in health and functional abilities. However, it does not necessarily follow that such persons function at a lower level than their younger adult counterparts. In fact, there is good evidence that the reverse is true.[12]

> The elderly [MR/DD] cohort includes some persons who in their youth were classified as "borderline" mentally retarded, who would not be labeled as mentally retarded today and who are, thus, not included in the younger adult cohort. [By comparison,] the younger adult cohort contains severely and profoundly retarded persons not expected to live to old age and who are, therefore, not represented in the older cohort. Thus, the two cohorts are composed of a substantially different mix of persons. The net result is that on the average, members of the older group function at a superior level to members of the younger group even through as individuals, members of the older group may be in the process of declining.

For these reasons, it is possible to integrate some elderly MR/DD persons into programs designed for younger MR/DD adults without substantially modifying the services offered to them or the expectations made of them. Thus, age alone should not be seen as a barrier to service integration.

However, some MR/DD elders do exhibit age-related changes—medically, behaviorally, or functionally—which require a special response. These changes may necessitate age appropriate services. In such cases, individuals can turn to either the generic aging services sector [or] the emerging sector of specialized services for elderly MR/DD persons.

The Generic Aging Service Sector. We now know, based on the direct experience of front-line professionals, and based on the results of a few preliminary studies, that there is a great deal of participation in the generic aging service sector by MR/DD elders.[13] We still lack good data about the full extent of this utilization and the nature of the services accessed. Most importantly, there is no documented track record as to the appropriateness of such services for MR/DD elders or the appropriateness of MR/DD elders for such services.

Utilization of generic aging services is consistent with our field's belief that MR/DD persons should interact to the maximum extent possible with the "ordinary" community. At different life stages this means different things. For children, integration means attending public schools and participating in mainstreamed classrooms. In adulthood, it means living in community-based and homelike settings and participating in the world or work. In old age, it may mean retiring from work, pursuing leisure time activities, and, in some cases, utilizing generic aging services.

"Consistent with the goal of community integration, having the diagnosis of mental retardation or developmental disability should not necessarily be seen as a reason for exclusion from the network of generic aging services.

[12]M.W. Krauss and M.M. Seltzer, "Comparison of Elderly and Adult Mentally Retarded Persons in Community and Institutional Settings," **American Journal of Mental Deficiency** 91 (1986): 236-243.

[13]See, for example, M.M. Seltzer and M.W. Krauss, **Aging and Mental Retardation Extending the Continuum** (Washington, D.C.: American Association on Mental Deficiency, 1987); M.M. Seltzer, "Assessing the Services Provided to Elderly Mentally Retarded Persons," paper presented in the 111th Annual Conference of the American Association on Mental Deficiency, Los Angeles, 1987; G.B. Seltzer and A. Wells, "Generic Day Programs for Seniors: An Untapped Resource?," paper presented at the 110th Annual Conference of the American Association on Mental Deficiency, Denver, 1986.

However, we should also not assume that generic services will be appropriate or desirable for ALL elderly MR/DD persons."

Thus, consistent with the goal of community integration, having the diagnosis of mental retardation or developmental disability should not necessarily be seen as a reason for exclusion from the network of generic aging services. However, we should also not assume that generic services will be appropriate or desirable for **all** elderly MR/DD persons.

The Specialized Service Sector for Elderly MR/DD Persons. Some MR/DD elders are not good candidates for generic aging services due to the nature of their disabilities or to limitations in the availability or capacities of generic aging services. Such individuals may be best served by specialized services for elderly MR/DD persons. Specialized services are either developed specifically for the purpose of serving this population or adopt this goal when a majority of the clients reach old age.

In 1985, when Marty Krauss and I conducted a nationwide survey of specialized programs for elderly mentally retarded persons, there were over 500 specialized programs in operation in the U.S. The rate of growth of this service sector during the few years prior to our survey was very rapid, largely in response to a population of mentally retarded persons who were aging in place in the age-integrated MR service sector and who possessed special age-related needs.

While specialized services are an emerging response to the needs of a subset of the population of elders with mental retardation, some professionals in our field have raised the concern that such services are too specialized and have the effect of isolating MR/DD elders from both the age-integrated MR/DD service sector and the generic aging service sector. Clearly the balance between specialization and integration is a delicate one. Therefore, no one response will be appropriate for all MR/DD persons in this stage of life. We do not yet have sufficient knowledge, however, regarding the best match between individual needs and the service sector that can most appropriately respond to these needs.

Summary and Implications for the Future

There are, in my view, four central challenges facing researchers, policy-makers, and practitioners in the immediate future.

First, we need to achieve consensus regarding the chronological demarcation by which to define "elderly." Once definitional clarity is achieved, we will be able to study the prevalence and characteristics of this population. Specifically, longitudinal studies are needed to track the aging process in this group and to distinguish cohort effects from individual differences.

Second, we need to carefully examine the impact of different service models on different subgroups of the elderly MR/DD population. In this context, we need to keep in mind the heterogeneity of the population. While they are predominately mildly and moderately retarded, their life experiences have often been very debilitating. This is the generation that either grew up in institutions or at home with few or no services.

"This is the generation that either grew up in institutions or at home with few or no services. There are no uniform approaches that will work well with all. Thus, a full range of services is needed, and we need better information as to how best to match a given individual with a particular mix of services."

There are no uniform approaches that will work well with all. Thus, a full range of services is needed, and we need better information as to how best to match a given individual with a particular mix of services.

Third, there are many elderly MR/DD persons who do not receive formal services. We do not know much about their characteristics or need for formal services. We also do not know a great deal about their families who have been providing lifelong informal support for them, and who may not be able to do so indefinitely. Long-range planning for this unserved population will not be possible without better information about who they are and what needs they have.

Lastly, I know that it is common for researchers like me to end remarks like these with comments on the need for more research. Regarding the aging MR/DD population, we run the risk of developing policies and services before we have a clear

understanding of the nature of the problem or the characteristics of the population. Our assumptions about elderly MR/DD people have at times been incorrect. This is an excellent opportunity for researchers, planners, and service providers to work together toward the common goal of developing high quality services for mentally retarded or developmentally disabled persons once they reach old age.

Robert M. Gettings

Barriers to and Opportunities for Cooperation between the Aging and Developmental Disabilities Service Delivery Systems

PREFACE

To understand the policies and problems of a particular service system, one must understand the environment in which it operates. The author's purpose here is to provide a meeting ground for the two systems of aging and developmental disabilities "in which we can identify cooperative points of interest and...develop a specific action agenda for pursuing those interests." In this paper he reviews federal and state policies that affect present and potential cooperation between the two systems. Mr. Gettings is executive director of the National Association of State Mental Retardation Program Directors, Inc.

Despite the fact that programs for aged and disabled persons generally are delivered through distinctive agencies at the state and local levels, society's basic approaches to dealing with chronically impaired individuals, as well as the specific legislative vehicles through which public assistance is furnished, are often identical.

Thus, for example, the primary sources of federal assistance for both elderly and disabled persons are the major social entitlement programs: Social Security, Supplemental Security Income, Medicaid, Medicare, Title XX social services. These two often vulnerable populations also are linked together in numerous federal transportation programs, federal housing programs, and food assistance programs. As a result, with increasing frequency, the fate of national legislative efforts to assist non-elderly persons with chronic disabilities is closely tied to the outcome of public policy decisions affecting elderly persons.

In many ways this linkage between society's approaches to aiding persons who are aging and persons who have disabilities makes logical sense. First of all, the frail elderly and the developmentally disabled often need a coordinated array of health services, income maintenance assistance, and other social supports for undefined lengths of time. Also, the problem of isolation from the mainstream of society and devalued public images that grow out of it are at the heart of our efforts to assist both the elderly and the developmentally disabled.

However, despite these shared concerns and significant similarities, there are differences, and it is important to recognize those differences.

1. Developmentally disabled individuals **usually** require an array of services over their entire lifetime, in contrast to chronically disabled people who are disabled later in adulthood or, in the case of elderly individuals, who need services only during the waning years of their life.
2. The developmentally disabled person needs a changing array of services during different periods of his or her life, in contrast to an elderly individual or a person disabled during adulthood who typically requires a gradually increasing intensity of services as they get older.
3. Due to the early onset of disability among the developmentally disabled, there is less likelihood of residual life skills which help to compensate for any impairments they have later in life.
4. While an individual with developmental disabilities usually requires a variety of specialized educational, vocational, habilitative services oriented toward the **acquisition** of basic life skills, individuals who are disabled later in life need a variety of specialized rehabilitation services aimed at restoring, reteaching, or substituting for previously existing skills.
5. The specialized services early in life that are

often needed by persons with developmental disabilities, such as infant stimulation, early education, corrective surgery or therapy, and vocational training services, are phenomena unique to the population.

Federal Policy Issues

It seems to me that as we look toward the future, those of us who are concerned about the welfare of the frail elderly and the developmentally disabled share a common interest in federal policy developments that impact on these two populations. Undoubtedly the most visible and certainly the most complex federal policy issue that needs to be resolved is the question of the federal government's role in financing long-term care services for persons with severe chronic disabilities.

MEDICAID. Nearly half of all Medicaid dollars—and that's now in excess of $42 billion a year—are spent on long-term care services. The Urban Institute has pointed out to us, for example, that the public share of nursing home expenditures increased between 1960 and 1982 from 28 percent to 58 percent of the total dollars expended, with Medicaid payments now constituting nearly 90 percent of all public outlays for this purpose.

Yet despite that growth in federal participation, current law has been very widely criticized, in terms of policy on behalf of the elderly and policy on behalf of the developmentally disabled, for being biased in favor of institutional solutions, as opposed to allowing recipients to receive services in their own homes or communities. There have been hundreds of bills introduced in Congress over the past ten years to rectify this so-called institutional bias, but thus far there has been little progress, I think mainly due to the fact that expanded long-term care coverage would obviously sharply increase the potential number of Title XIX recipients and, consequently, the total cost to the federal government of such services.

Failure to address that basic statutory dilemma, however, is not necessarily going to curb the growth in Medicaid outlays, since the ever-increasing demand for long-term care services, in my view, can't be satisfactorily solved through institutional services. It seems to me that, regardless of whether sweeping or only incremental changes are contemplated, those of us who are concerned about the frail elderly and other disabled individuals must collaborate more closely if an equitable solution is to be found to the current policy morass.

One near-term priority for both groups must be to protect existing Medicaid home and community care coverages, with particular emphasis on the section 1915(c) waiver program. The administrative constraints the Health Care Financing Administration has placed on using the Home and Community-Based Waiver Program and other similar state plan options [have] limited the financing alternatives available to the states. Over the next couple of years continuing administrative pressure, litigation, and selected statutory amendments will be needed to safeguard present avenues for funding community-based long-term care services through the Medicaid program. Meanwhile, more substantial changes in federal law can be pursued in order to solidify and further expand the base of federal support for long-term care services.

INCOME MAINTENANCE POLICIES. Income maintenance policies, as they affect OASDI and SSI recipients, demonstrate another area in which organizations representing disabled and elderly Americans share a common interest. Efforts over the past few years to preserve existing benefits have been largely successful. In addition, the circumstances under which a disabled recipient may retain his or her benefits status have been liberalized somewhat under the Social Security Disability Benefits Reform Act of 1984[1] and the Employment Opportunities for Disabled Americans Act of 1986.[2] Now it is time to map a broader policy agenda for Social Security and SSI reforms in the years ahead.

HOUSING, TRANSPORTATION, AND FOOD ASSISTANCE PROGRAMS. Finally, federal housing, transportation, and food assistance programs have a significant impact on both aged and disabled persons living in the community. In general, federal housing and transportation

[1] P.L. 98-460.
[2] P.L. 99-643.

assistance have been hard hit by the fiscal austerity policies of the Reagan administration. Some efforts are currently underway to recoup losses sustained over the past six years. But, in this observer's view, a more fundamental reassessment of the federal government's role in promoting the availability of appropriate housing and accessible transportation systems is sorely needed.

STATE POLICY ISSUES

The field of developmental disabilities is in the midst of a historic change. We are moving from a unitary institutionally-based service system to a diverse multi-faceted network of community-based services.

The increased dominance of community-based services poses for us some very interesting challenges, I think, for the years ahead. Instead of simply overseeing the operation of several state operated, comprehensive treatment facilities, state officials are now faced with the challenge of managing a pluralistic, diverse network of services that are offered, in most instances, through for-profit vendors.

The kinds of managerial skills that are necessary to perform this new role are significantly different than those historically required on the part of the agency personnel. State officials now have to play a much more pro-active role in systems management, rather than simply nurturing the continued expansion of services.

These changes, of course, are taking place in an evolutionary fashion. The director of a state MR/DD agency cannot afford to ignore the operation of state residential facilities, as the results of the recent federal ICF/MR look-behind surveys remind us. Nor can he or she over-emphasize management efficiency to the detriment of other high priority systemic goals, such as program quality and the expanded availability of services. The key then is to strike the proper balance between competing demands on the agency's resources, both fiscal and human.

Among the kinds of issues that we are faced with are these:

IMPROVED ECONOMY AND EFFICIENCY. State MR/DD agencies increasingly are being forced to find more effective and efficient methods of using existing resources in an environment where demand for services is growing at a much faster pace than the dollars to support such services. During the period of rapid program development in the mid to late 1970s, economy and efficiency often were of secondary concern. [In fact,] the wide discrepancy between institutional and community service costs make the expansion of community services quite attractive in most states, especially since federal funds could be used to finance a major portion of the cost of such expansion. As community costs have risen and the emphasis has shifted from serving former institutional residents to addressing the needs of persons already living in the community, state MR/DD agencies have encountered stronger demands for economy, especially from state budget offices and legislatures. These demands have led to a search for less costly service options and tighter controls on the expenditure of state funds.

THE RAPID EVOLUTION IN SERVICE MODALITIES. State MR/DD agencies are being challenged to foster an environment that encourages experimentation and the adoption of new program formats. For example, there are efforts underway in any number of states to re-program day service dollars into competitive and supported employment programs for persons with developmental disabilities. These changes are certainly essential to the achievement of long-range systemic goals, but they may also pose managerial problems. For example, our increased reliance on Medicaid as a funding source and that source's requirement that we provide something called "active treatment" on behalf of people using only the developmental model, may not be appropriate for the population that needs generic aging services. This is a dilemma we will be facing in the next few years.

ACCOMMODATION TO CHANGE. Because of the rapid changes which are taking place in the delivery of services, state MR/DD agencies are having to re-examine their own internal structures and operations to assure that they permit the agency to effectively carry out its stated goals and priorities. For example, management information systems must be altered to keep abreast of changing program formats and goals. Also, internal staffing levels and assignments often have to be changed to reflect shifts in the work load or new agency goals.

GUIDING CHANGES IN THE SERVICE DELIVERY NETWORK. Clearly, community service systems are constantly evolving in most states. "Mom and pop" providers are being replaced by larger, more sophisticated agencies. For-profit entities and interstate providers are beginning to make inroads in some states. Increased specialization among service providers appears to be the trend in other states. Changes such as these can have a powerful influence on the capabilities of the service system to meet the needs of disabled persons and, therefore, must be carefully tracked and, where necessary, guided by the state agency.

EMPHASIS ON QUALITY. Now that community services have become a more prominent part of state systems, I think it is incumbent on us to give greater emphasis to program quality and client outcomes. The role of the state MR/DD agency is rapidly changing from a developer of service to a regulator and evaluator of services, and this type of role is nowhere near as popular as shelling out money for new programs. The point is that institutional services can no longer be used as the primary yardstick for judging the quality of community services. Instead, what we are being asked to do is to compare community programs to community programs, and this is a more challenging assignment.

In Conclusion

To conclude, the fields of aging and developmental disabilities are both undergoing tumultuous changes. There is increased demand, coupled with rising expectations and uncertainties about what role the federal government will play in the overall support for these services. The demand is placing enormous pressure on both delivery systems. It is not clear how these issues will play out, but I would like to suggest that one of the big challenges before us today is to find ways in which we can identify cooperative points of interest and develop a specific action agenda for pursuing those interests.

Daniel A. Quirk

State Partnerships to Enhance the Quality of Life of Older Americans with Lifelong Disabilities

PREFACE

Building a stronger, more effective service delivery system to meet the needs of those increasing numbers of older Americans who have experienced lifelong disabilities takes planning, but the time will be well spent. This article focuses on the key questions state aging and MR/DD systems should consider in "sorting out the most appropriate roles and responsibilities for the two networks in serving this population." Dr. Quirk is executive director of the National Association of State Units on Aging.

America faces a demographic revolution. The population is aging to such an extent that our social, political and economic structures and institutions will over the next quarter of a century, need to adjust in rather significant ways to respond to these "new generations" of older Americans.

We have all heard and read the statistics. There is no need to repeat them here. However, we do need to focus our attention, energy, and resources on the new opportunities that this "aging America" provides for us [and] how we can work together to enhance the quality of life for those increasing numbers of older Americans who have experienced lifelong disabilities.

To Build a Stronger and More Effective Service Delivery System

We believe, of course, that one of the primary resources available to us as we struggle to find appropriate public and private responses to an "aging America" is the network of state and area agencies on aging established under the Older Americans Act.

From its inception, the Older Americans Act was designed to provide services to older persons who were not adequately served by other public and

Editor's Note: Paper delivered by Sara C. Aravanis, director of the Center for State Action on Elder Rights, National Association of State Units on Aging on behalf of Daniel A. Quirk.

private systems. But, most importantly, it was also intended to establish an institutional advocacy at the federal, state, and local levels to encourage all service systems to be more responsive to the needs of the elderly.

We should point out, however, that the act did not come about without debate. In 1965, as it was considering older persons and their needs, the Congress met with two conflicting viewpoints. On the one side were the traditional public welfare advocates who argued that the existing public welfare system, if better funded, would do an adequate job for meeting the needs of the elderly. The other side held out that the aged could expect to receive the attention they deserved only if there was a very specialized program designed particularly with their needs in mind.

A compromise response of the Congress in 1965 made the Older Americans Act and its network of state and area agencies one of the most dynamic human service systems today. We have a mandate to provide services, to provide a whole range of services to older people. We have a limited amount of funds. We have a very broad job. We have a mandate to make other service systems work on behalf of the people we serve.

The importance of the Older Americans Act stems in large part from three facts. First, it is the major categorical social and nutrition services program provided in federal law for America's elderly. Second, the administrative network—the Administration of Aging at the federal level and the state and area agencies [on aging]—has importance far beyond the particular monies that are spent and the services it stimulates. Of course, compared to the major income transfer programs for the elderly, the Older Americans Act has very little budget prominence. Yet this administrative network, through its channeling and monitoring of federal funds, works to assure the establishment of a comprehensive and coordinated system of services, all the while encouraging other public and private non-profit and for-profit agencies and organizations to play their part in better meeting the needs of the nation's elderly.

The third aspect which sets the Older Americans Act apart [from other programs] is that it provides an integral stimulus, through a partnership of federal government with state and local governments, for promoting the allocation and redistribution of resources on behalf of the elderly beyond those granted by the federal government.

But this description of the administrative network severely understates the importance of the act's policy mandates. The network of state and area agencies on aging does substantially more than simply administer the act's funds. Rather, it has developed into a set of complex state and local political and administrative structures with major responsibilities, such as providing advocacy for the aged; identifying community and individual needs; identifying, pooling, and coordinating funds beyond those granted by the federal government under the Older Americans Act; and developing community-based service delivery systems.

Changing and Expanding Role of the Aging Network

In recent years, the administrative network stimulated by the Older Americans Act has entered a new and exciting stage in its development. We are now in a period of expansion, not in terms of structures or services, but in terms of policy arenas in which state and area agencies on aging must become involved on behalf of older persons. This policy expansion is critical to the future role of the network and its capacity to respond to the changing needs of the older population.

Thus, today the agendas of the state and area agencies on aging need to be as varied as the needs of the older population: **long-term care system development, access to adequate and affordable health care, older worker employment opportunities, affordable housing options, ombudsman services to institutionalized older persons, adequate income maintenance programs, strengthened informal family support systems, protective and legal services development.**

Today state and area agencies on aging must be in a position to assist:

1. State and local public administrators in all fields (health, social services, housing, legal, nutrition, energy, income, etc.) who are facing the demands of the aging of America.
2. State and local elected officials who must make increasingly difficult decisions about the allocation of public resources.
3. Developers of life care communities and shared housing arrangements.
4. Employers who are creating flexible work arrangements and retirement schedules.
5. Companies which are developing health-related products and aids for independent living.

6. Insurance firms which are developing long-term care insurance.
7. Housing developers who are establishing complex service arrangements as their residents age.
8. Medicare health maintenance organizations (HMOs).
9. Hospitals which are acquiring and developing nursing homes, foster homes, and home health services.
10. Managers of public and private pension plans.
11. Nursing home chains which will increasingly care for the growing numbers of the oldest of the old.

Working Together to Meet the Challenge

How can the aging network and the MR/DD network work together to enhance the quality of life for a significant component of these "new generations" of older persons—those who have experienced lifelong disabilities?

Both networks have legal and moral responsibilities to ensure that appropriate public and private responses are made to this group of older persons. We must initially define the population to be served, and their needs for social and health services, income supports and advocacy, to ensure self-sufficiency and independence. And we must begin the essential task of sorting out the most appropriate roles and responsibilities for the two networks in serving this population.

General Considerations for Effecting Change

1. ADMINISTRATION AND MANAGEMENT. Both networks are characterized by state diversity in the organization of service systems, with the MR/DD system even more varied from state to state than the aging network. What implications does this diversity have on the capacity of the systems to work together? Services provided by the Older Americans Act cannot be means tested, but rather are open to all older persons sixty plus in need of services. There is, however, statutory and regulatory language requiring targeting of resources on low-income and minority older persons. How do these provisions impact on our interaction? Both networks have a strong planning focus. How can the networks better cooperate to perform this critical function for their respective and overlapping constituencies? How do our agendas intersect in the work we are going on information systems, on forecasting models, on data collection? Both networks have responsibilities for staff development and training. What opportunities does this provide for interaction between the two?

ADVOCACY AND PUBLIC AWARENESS. We both have a common advocacy goal and function relating to quality institutional care when institutionalization is necessary. How can these advocacy missions intersect? Both networks have the responsibility to combat public misconceptions and biases about their constituencies. What are the common elements of these public awareness missions? We have a responsibility to advocate for state and local regulations which encourage and do not inhibit the development of responsive service systems. What opportunities does this provide for a united agenda?

SERVICE SYSTEMS DEVELOPMENT. Both networks focus on the development of a full continuum of direct services required to respond to the specialized individual needs of the frail or the more self-sufficient of their clients. What aspects of this continuum are common to both populations? Both networks put in place mechanisms for assuring accessibility to needed services. How can these access points interrelate? We are both involved in organizing and supporting similar structures for service delivery, such as case management, individual assessments, care planning, family supports. How can these approaches be translated into model projects and demonstrations? A common policy and program agenda? Both networks share a common agenda in the housing/living arrangements arena—residential services, adult houses, foster care, board and care, apartment and group houses, etc. What opportunities are there for joint initiatives? Both networks seek to expand the availability of community services, such as transportation, adult day care, in-home services, and respite care. To what extent do the same providers serve both populations?

POLICY. Both networks share a common interest in expanding home and community—based services. Is a joint federal and/or state specific Medicaid

strategy possible? Both networks share a common interest in employment policies. What implications does this have for JTPA [Job Training Partnership Act] strategy? Or a joint strategy of working with the private sector? Both networks share a common interest in adequate income maintenance programs. What implications does this have for a joint federal and state specific SSI strategy? Both groups share a common objective of creating a more rational balance of public resources supporting institutional and community-based care. How can this common ground lead to the reversal of institutional biases in federal and state policies? Both networks are working to expand private sector funding and third party reimbursement mechanisms for needed services. How can we work together to expand program resources?

In Summary

I think it is clear that this "sorting out" process needs to occur at all levels in our structure at the federal, state, and local levels. The group assembled here can provide a recommended plan of action to build on the strengths of our respective networks and to overcome the inevitable roadblocks that are encountered when two systems begin to work together. We are convinced that our combined strengths and mutual commitment will result in significant progress in the years ahead.

Part three: Decision-Making and Public Policy in Aging and Disabilities: Problems, Dilemmas, and Barriers

Issues and Strategies Discussion Groups: Problems, Dilemmas, and Barriers

Discussion Group I-a:

Management and Administration

Discussion Leader:
John L. Stokesberry / Southeast Florida Center on Aging, Florida International University

Resource Persons:
Matthew P. Janicki / New York State Office of Mental Retardation and Developmental Disabilities
Cathy Michaelson / National Institute on Community-Based Long Term Care, The National Council on the Aging, Inc.

Alike, state agencies in the aging and development disabilities fields are becoming more concerned about the implications of the nation's older developmentally disabled population and the long-term care-related problems of older Americans with lifelong disabilities. In an attempt to provide some amount of assistance to older developmentally disabled Americans, their families and their caregivers, state aging and MR/DD agencies need not operate at cross-purposes, but rather must act as vital, sympathetic, and helpful allies.

Where do the solutions lie? As a first step toward being able to develop appropriate responses, Wingspread participants concentrated on the identification of issues in the management and administration arena that, if properly addressed, would enhance considerably the ability of state aging and MR/DD agencies to initiate cooperative planning and service approaches for developmentally disabled older Americans. The following major themes emerged from the discussion:

1. INTERAGENCY COORDINATION AND COMMUNICATION. Increased knowledge and a heightened awareness on the part of state aging and MR/DD officials and agency staffs about each other's authorities, budgets, policies, implementing structures, functions, priorities, mandates, and target populations are necessary if the nation is to make any progress toward achieving service integration goals on behalf of older Americans with lifelong disabilities.

Part of the problem has been the result of viewing each program as distinct and unrelated. Attention must be directed to the fact that the MR/DD population is by and large unknown to the aging network. Once problems and needs of this population are better understood, professionals in the fields of aging and developmental disabilities will be able to act much more forcefully and effectively on issues of immediate shared concern.

On a broader scale, aging and MR/DD agencies have different means of regulating and monitoring their respective service systems. Because of the interplay among legislative policies and regulations, closer coordination and communication between agency staffs are needed to improve statewide planning, whereby overlaps and gaps between and among programs can be identified. State aging and MR/DD officials ought to define and establish a formal relationship where cross membership on advisory councils is encouraged and where coordination implies a recognition of mutual interests, a shared concern for the welfare of the aging with lifelong disabilities and their families, and a willingness to work cooperatively to ensure their well-being.

In all these areas, state aging and MR/DD service systems should respond to the challenge by clearly separating that which each can accomplish alone, that which neither can accomplish at all, and that which can be accomplished only by acknowledging and using the combined resources of both systems.

2. TRAINING AND EDUCATION. In-service training of professionals, para-professionals, and informal care providers—and education of the public at large—are extremely important in terms of eliminating stereotypes, myths, and other barriers serving to impede effective service delivery to older persons with lifelong disabilities. The search for

solutions, both immediate and long-term, must include a commitment to cross-training and development of a combined training plan that can accommodate different stages and levels of knowledge and needs of diverse groups.

Training and education form the core of a combined advocacy effort. State and regional training should be on our immediate agenda so the problems before us can be properly understood and taken seriously by all. States can begin to act now by piggybacking on conferences and training sessions already on the calendar. In view of the potential for turf protection, training may be conducted by an appropriate third-party, or by the growing number of professionals with integrated expertise in aging and developmental disabilities.

At the same time, attention must be directed to finding agreement on definitions, language, and terminology used by both aging and MR/DD systems.

3. **PUBLIC POLICY.** Money needs to be packaged differently and new sources of funds need to be found for serving older Americans with lifelong disabilities. The search for funds should be guided by the goal of creating an integrated service delivery system, rather than by rigid adherence to the existing regulatory system.

Attaining that goal requires that there be consensus on service population definitions.

Existing services fail to meet the needs of a great many of the nation's older developmentally disabled citizens due in large part to categorical program restrictions and restrictions in eligibility, such as age criteria. State aging and MR/DD agencies have no choice but to limit services to selective parts of the population, thereby risking duplication of service and administrative costs. State agencies are caught in the dilemma of funding following the service, rather than following the people who need assistance.

Demonstrations should be funded to test the feasibility of initiating integrated systems of service and to expand the range of alternative service approaches and provider pools available. Active treatment should be tailored to the needs of the individual. For example, even though an older developmentally disabled person may need help in keeping active, he or she does not necessarily need to learn to tie his or her shoe or to learn to spell.

Categorical programs should be made more coordinated and coherent, with greater emphasis on reconciling eligibility criteria.

4. **ADVOCACY/LEGAL SERVICES.** Before any significant policy changes can be made, state aging and MR/DD advocates must be linked together in common cause. This will require linking Older Americans Act legal services with MR services, linking aging and MR/DD ombudsman programs and information and referral services, identifying those who will be in need of service, providing transition services from the MR/DD system to the aging service system, and providing a buffer for aging parents.

Discussion Group II-a:
Service System Development

Discussion Leader:
Sara C. Aravanis / Center for State Action on Elder Rights, National Association of State Units on Aging

Resource Persons:
B. Stockton Clark / Program Initiatives Unit, New York State Office for the Aging
Marsha Mailick Seltzer / School of Social Work, Boston University

Older Americans with lifelong disabilities, it should be emphasized, have problems that are more similar to than dissimilar from those of the rest of the nation's elderly population. The matters of concern to the elderly disabled and their caregivers such as housing, employment, leading a life of dignity, long-term health care, and the other life essentials are of equal concern to all.

It is important, of course, to recognize that because of the varied and changing needs of older individuals—disabled and non-disabled alike, affluent and poor, majority and minority—services must be flexible and responsive in order to be available to all who need them. Even when service programs are available, persons who need them may be unaware of them.

In order to better serve those who have traditionally not been served, a major challenge state

Elderly/MR/DD Service Model

Aging Network	Joint Funded Aging and MR/DD Service System	MR/DD Service System
Aging network funded supportive services, such as senior centers and adult day care programs	MR/DD funded supportive services . . . . . . Aging network funded supportive services	MR/DD funded supportive services, such as sheltered workshops and vocational programs
Needs: Low supervision and behavioral/medical support needed.	**Needs:** Medium supervision and behavioral/medical support needed.	**Needs:** High supervision and behavioral/medical support needed.

Fig. 1. Concept of an integrated service system must be thoroughly explored to determine appropriate linkages between state aging and MR/DD service systems, and their interface with programs in other agencies, such as mental health.

Source: David H. Rodriguez, client programs administrator for the Developmental Services Program Office, Florida Department of Health and Rehabilitation Services.

aging and MR/DD agencies face is to understand and evaluate the total array of existing programs, benefits and services, to identify strengths and weaknesses, and to work for more effective coordination of resources resulting in greater benefits to elderly disabled citizens.

The Barriers to Coordination

1. MISUNDERSTANDINGS AND MYTHS. Many people—young and old alike—view persons with mental retardation negatively, rejecting them from the fabric of society because of limitations in intellectual understanding and awareness, emotional development, etc. Mental retardation is all too frequently defined in terms of severe or profound disability, when in truth marked differences among people do exist, and fully 80 percent of adults with mental retardation are only mildly retarded. Failing to recognize individual potential, Wingspread conferees concluded, leads to the concentration of resources in institutions, rather than in more positive community-based alternatives. More cross-training is needed to break down this barrier.

Another issue pointed out by Windspread participants is the fear expressed from the aging side that the MR/DD system is "dumping" clients onto aging services, using up scarce aging funds, without consideration for coordination and combined assumption of responsibility. More education is needed to dispel this perception, Wingspread conferees concluded. In addition, the continuing problem of misunderstandings about MR/DD

clients, who they are, how they fit into service programs, and so on needs to be addressed by both systems.

Knowledge, learning, and information are the raw materials needed for breaking down barriers. For a system of integrated services to function, state aging and MR/DD service systems must be able to reach some common understanding on complex issues. Education helps form these common understandings.

2. SPECIFIC SERVICE ISSUES. To get a coordinated system off the ground, state aging and MR/DD agencies need to have some idea of what appropriate activities for older persons with lifelong disabilities are, what services are available, and which system is responsible for coordinating service delivery.

More education is needed about the aging network and its make-up of services. MR/DD agency staff often have little idea of what the services are that are provided through the aging network, so that there may be little impetus to participate in a coordinated system. What are the options available for the recipients?

There was general agreement by Wingspread conferees that state aging and MR/DD agencies need to look at the full range of options for serving mature adult persons with lifelong disabilities. It may not be desirable to rely exclusively on any one part of the human services system to meet the needs. Not all elderly with disabilities require the special care that the MR/DD service sector can provide; moreover, the various special services for the elderly provided through the aging network may not always meet adequately the needs of those who are seriously impaired by a physical or mental disability. There is no uniform standard solution, Wingspread participants concluded.

As can be expected, case management services are critically important to older persons with developmental disabilities. There was some concern voiced by Wingspread participants, however, that state aging and MR/DD service systems apply different meanings to the term case management and the range of activities with which it is associated. A better understanding of what it means to both networks and what it can and cannot do will contribute to the fostering of increased opportunities and choices for older Americans with developmental disabilities. A major aspect of that, of course, is determining the focus of responsibility. While there is no question that the aging network can and certainly does play an important role, Wingspread conferees concluded that the responsible party for this client group should be with the MR/DD system.

Currently, more than 60 percent of the population with developmental disabilities are not being served by the MR/DD service system; they are aging in place in two-generation geriatric families. More case management services are needed to forestall a potential crisis when the parents are no longer able to care for their mature adult offspring.

Conflicting federal and state service mandates and program eligibility restrictions are additional barriers to coordination, Wingspread participants noted. For example, in several states, every person with a significant disability is entitled by law to be assigned a case manager. In other states that is not true. States need to identify what is particular to a state aging or MR/DD program, statutory prohibitions that may exist, operating practices, and requirements for specific services in order to eliminate or reduce conflicts.

3. JOINT FUNDING ISSUES. Concern was voiced by Wingspread participants about the problem of barriers in Medicaid policy that prohibit the "coming together" of Medicaid and Older Americans Act funds to follow a client. In order to better serve this population, funding should follow a client no matter where the services are contracted from.

In an attempt to focus more resources on the problems that are urgent, state aging and MR/DD agencies need to jointly explore a more intensive program of initiatives that could result in vastly improved service arrangements for older Americans with developmental disabilities. Federal and state policy-makers are receptive to prototypes and models as guides for trying out promising ideas.

Discussion Group III-a:

Advocacy and Public Awareness

Discussion Leader:
Elizabeth P. Rouse / The Joseph P. Kennedy, Jr. Foundation

Resource Persons:
William E. Jones / American Association of University Affiliated Programs
Edward F. Ansello / The University of Maryland Center on Aging

The significance of advocacy and public awareness becomes readily apparent in attempting to introduce a collaborative, integrative systems development effort. As organized advocates, national and state aging and MR/DD organizations can constitute a powerful influence as partners. The best results are obtained when all work together as a team to develop an advocacy strategy—which then becomes the basis for getting across important points about elderly and developmentally disabled Americans to influential legislators, government policymakers, concerned groups and special interests, and the public at large.

Of all the tools at hand, the public's support for the future of older Americans with lifelong disabilities is the most powerful. Instead of allowing stereotypes and misconceptions to predominate, appropriate advocacy and public education can stimulate more active and conscientious participation by government in safeguarding the lives of elders with developmental disabilities. In attempting to get a coordinated advocacy/public awareness program off the ground, however, state aging and MR/DD agencies are likely to encounter a variety of obstacles which must be accommodated. These include:

1. **DEVALUATION OF ELDERLY AND DEVELOPMENTALLY DISABLED POPULATIONS.** One of the most disturbing problems that has to be dealt with directly is that America historically has not valued either of these populations in any significant way. In many walks of life people look at those populations as not being particularly attractive.

The lifelong segregation of today's population of older developmentally disabled from the larger community is a very real problem. This will not necessarily be true for those who are growing up today and are being integrated, but for the group of people who are now elderly, those who spent so much of their lives in institutions, the search for solutions must take into account their unique needs. The model chosen for today's elderly disabled may not be the same as for succeeding generations.

Despite the progress that has been made in the past two decades, serious attention still must be given to dispelling negative attitudes: negative attitudes of the elderly advocates toward DD, negative attitudes toward aging and developmental disabilities. And that has a lot of implicatons when it comes to the kind of advocacy that is needed and the kind of public awareness that state aging and MR/DD service systems are concerned with.

2. **FINANCING.** The separation of current services which are based on categorical problems and separate funding streams and are restricted to serving preferential client groups has kept state aging and MR/DD service systems separated, too.

Another major problem is lack of incentives to serve the older developmentally disabled population and lack of mandates. Related to it is the whole turf issue: the best way to characterize it may simply be to use the term "mental geography." In short, there is not enough space within some people's thinking to consider this population, to allow them to move beyond where they have always had to concentrate. The tunnel vision, if you will, that bureaucrats are sometimes accused of having...

Finally, administrators, realizing that reforms in the Medicaid waiver program are needed, must plan accordingly. Significant change will be difficult, if not impossible, without constant interaction between the two systems.

3. **FAMILY CARE SUPPORTS.** A big concern has to do with the need for training and education of caregivers who are not family or friends, those who are hired for institutions and community-based homes, as well as volunteers. Recruitment issues will also have to be addressed very soon in light of the greater number of elderly developmentally disabled persons who will require assistance than have ever been in the system before.

Another salient issue to be considered is that the privatized system of caregiving has worked so far.

Families have cared for their disabled offspring and probably will continue to care for them at home so long as they are able, so there has not been much incentive to try to develop something different.

Therefore, it is crucial today for efforts to assist family and other caregivers to continue. Most of these caregivers will be women. In this regard, steps needs to be taken to strengthen the involvement of men in the caregiving aspect of family.

One other issue seems of particular importance. It is more humane, more effective, and less costly to **prevent** lifelong disabling conditions than to treat their effects. This nation pays a high price for its inattention to prevention.

4. GOAL CLARITY. What are society's aspirations for the aging and for individuals with developmental disabilities? Perhaps one of the most crucial barriers is the realization that we as a nation do not really know what our quality-of-life goals for older Americans with lifelong disabilities are. We need to know in what direction we are moving.

Discussion Group IV-a:
Public Policy

Discussion Leader:
Colleen Wieck / Minnesota Governor's Planning Council on Developmental Disabilities

Resource Persons:
Thomas Rose / National Center on Aging and Disabilities, The University of Maryland Center on Aging
Marilyn Moon / Public Policy Institute, American Association for Retired Persons

"Policy" is defined as "what government should do, what government says is being done, and what actually happens." There are values underlying policies related to older Americans with lifelong disabilities. Without making any claims for definitiveness, policy-makers must recognize at the outset the importance of misuse and abuse of terminology. Preference should be given to the term "older people with developmenal disabilities" or "people with disabilities who are elderly," as opposed to using such terms as "the elderly developmentally disabled" or "the disabled."

A pertinent related value is to reaffirm society's commitment to individuals and to integration of persons outside the mainstream. Policy-makers also need to recognize the importance of informal supports (friendship and family) as being preferable to paid caregiving. Continuity in lives is far more important and critical than shift patterns or staff turnover. The term "array of services" communicates better than "continuum of services." Array emphasizes the type and level of supports needed by the **individual,** whereas the term "continuum" implies people having to move through a series of buildings which connotes discontinuity.

We need to treat people with respect and dignity, rather than as objects of abuse, neglect, pity, or charity. We need to recognize that in all of our lives, we must have the opportunity to negotiate. Unfortunately, for people with disabilities we tend to regulate and make rules to govern lives (for example, a universal retirement policy is a regulatory approach, when it should be a decision that is individually determined).

We need to provide opportunities for choice and exercising personal rights—people with disabilities who happen to be older should be given the chance to express "I need, I want, I like, I dislike."

If we are serious about improving the quality-of-life of older persons with lifelong disabilities, we must think about providing them a decent place to live—a home, not a service setting, not a concrete dormitory.

We need to provide opportunities for people to contribute to the community and be productive. Group homes and sheltered workshops are no longer considered to be state-of-the-art services.

State leaders in aging and developmental disabilities have a commitment to a reoriented philosophy. They seek promising new opportunities and the challenge of serving older Americans with lifelong disabilities more effectively.

The following highlights some of the major policy issues that will have profound implications for long-range planning:

1. ISSUES OF INDIVIDUALIZATION AS OPPOSED TO CONGREGATE PROGRAMMING. The service orientation of the MR/DD system is based on individualization: individualized client

assessment, individualized planning, and individualized service delivery. By contrast, programs and services supported by the aging network are mainly provided in congregate settings. Individualized assistance to older persons is not frequently done in the aging system because of the nature and size of the client population. As a matter of policy, should there be more or less congregate care for clients in both systems? To what extent is a "one-on-one" approach really possible?

Members of the aging system need greater understanding of the meaning of "normalization." Needs for service vary widely among individual clients. What does "normalization" actually mean for the different variations? The field suffers from lack of valid measures of "norms," making assessment of individual needs difficult. At present, ethnic variations of "normalization" are lacking.

We should be seeking more intensive involvement of clients in planning and decision-making. The function of agencies in both the aging and MR/DD systems as "surrogates" or "advocates" needs to be re-examined as to its effect on individual decision-making. What do we know about the "loss" of individuals in large service systems? What is the optimal scale of operation to preserve individual options? Differences between the "active treatment" approach and the "path of development" approach need to be studied carefully. Which is better for older developmentally disabled clients?

Finally, we must clarify respective roles and functions of MR/DD and aging service systems in service planning and delivery.

2. **MEDICAID POLICY.** The extent to which integration of services can be carried out on behalf of older persons with developmental disabilities will be affected by Medicaid policy. Right now money drives policy. Money drives services. Money drives people to where the services are. Medicaid clients in nursing homes and other institutional settings are often the "more difficult" clients. Are they in danger of labelling and thus being lost to service systems? We need to examine the effects of particular diagnoses as they are tied to funding.

Concern was voiced by Wingspread participants about the problems of Medicaid's bias toward institutionalization. Despite the fact that the Medicaid home and community-based waiver program was an attempt to solve some of those problems, federal and state grant restrictions and regulations seem to inhibit the provision of alternatives. The need for home health care is clearly increasing among aging clients. What can be predicted with regard to elders with developmental disabilities?

We need to take steps to establish a national program of entitlement for long-term care. This will entail study of the various available forms of long-term care, the issue of financial protection vs. services rendered, and attaining further knowledge of the needs of the current "invisible population" of persons with developmental disabilities now in board and care homes, "warehoused" somewhere, or among the homeless.

3. **SUPPORT INDIVIDUALS, NOT SERVICE SETTINGS.** We need to understand better the difference between "the setting" (segregated vs. integrated) and "supports." It is important to clearly separate the supports available from settings available in order to truly serve individual differences. Failure or dumping of clients may occur in an integrated setting simply because of the lack of adequate supports. The setting might be fine. What we have to do is make sure we provide those needed supports.

4. **QUALITY AND PERSONNEL ISSUES.** Attention needs to be given to recruitment, training, pay, turnover, and licensure of caregiving manpower. We need a systematic approach to the education and training of all classes of providers, and we should include new graduates and beginning practitioners in educational programs. Effective training has been shown to reduce staff turnover. Does the MR/DD system offer training that is more sophisticated and complex with regard to understanding the needs of the older American with lifelong disabilities than that provided by the aging network? The need for manpower at all levels calls for a thorough re-assessment of existing training and definition of needs for cross-system training. Is licensure and/or certification for aides, paraprofessionals, and other caregivers necessary? Monitoring and control of personnel and quality of services must become a key activity of both systems.

5. **MECHANISMS.** Are the service agencies over-

professionalized? Do their decisions actually control how funds are used to the possible detriment of clients? The politics of this issue need thorough airing. The potential of a family support program as opposed to services for elders with developmental disabilities should be weighed carefully. What are the advantages and disadvantages of a cash support program for families compared to providing them services? Families need support services to make wise decisions. Perhaps elders with developmental disabilities need a combination of both.

How should the public systems in both developmental disabilities and aging work with the voluntary agencies? There are many voluntary agencies in the developmental disabilities field, less so in the field of aging. However, many voluntary agencies do provide services for their own constituencies who are aging via United Way and other funding sources.

Issues surrounding means testing need to be thoroughly examined. Means testing for the aging could mean loss of benefits to some. When a client reaches the category of "old age," which system should be the "primary payer?" This issue relates to the question of "cost-sharing," as well as issues surrounding appropriateness of system functions to individual clients.

6. HOUSING AND TRANSPORTATION POLICIES. There is a need to rethink housing and transportation policies to assist individuals with lifelong disabilities in remaining a part of their community. Does the federal role need revision? Specifically, states should study the similarities and differences between the various kinds of community-based residential facilities currently available and determine their appropriateness for clients with developmental disabilities. Wherever possible, segregation of clients with developmental disabilities should be avoided. It is essential that aging and MR/DD systems do whatever can be done to give clients first choice in choosing living arrangements. Small group homes can be very isolating for residents. Residential arrangements should not dictate or limit the full array of needed services.

7. RESEARCH AGENDA. Most elderly developmentally disabled clients are forced to live in poverty. We have little knowledge about the 60 percent of elders with lifelong disabilities presently unknown to the system. Will they be forced into impoverishment as well? Although "60 percent" is an approximate estimate of the currently unknown and unserved population of elders with developmental disabilities, there is no certainty that such a figure is truly representative of all localities. We should take precautions against error. There is a need for continuing research at all levels.

Part four: Effective State Responses

John L. Stokesberry

Best Practices for Integrating Service Delivery to Older Persons with Developmental Disabilities

FOREWORD

Helping more people to understand the problems and needs of older persons with lifelong disabilities, and to participate in effecting the changes which can move the aging and MR/DD systems to a much closer integration is an important part of the planning process. "When it comes to best practice in integrating our programs," Stokesberry notes, "best practice is what works, and what works is common sense, and common sense starts with education and allaying fears and keeping it simple." In this context, the author offers a few ideas for integrative, collaborative action. John L. Stokesberry is a program director for the Southeast Florida Center on Aging, Florida International University. A former state unit on aging director for the state of Florida, he also has extensive experience as a practitioner and manager in the developmental disabilities service system.

The concerns grow day by day. The greatest thing we have learned over the past few years is how much we really do not know about older persons with developmental disabilities. Our ignorance is not limited to mere lack of familiarity with one another's programs or who is doing what, but to far more basic questions of how many older persons with developmental disabilities really are out there? Where are they? What do they really need? And how can they get it?

We hear a lot about: "If this percentage of the general population is developmentally disabled, and if this percentage of the general population is aging, then there should be this many elderly with developmental disabilities." Or, "Our best estimation of the number is..." We have very little in the way of hard data as to the numbers.

A recent study done in Florida (the results have not yet been published) estimates conservatively there may be as many as 15,000 individuals who meet our definition residing in Florida. A check of our client information system positively identified less than 1,200 clients known to fit the description, a figure a far bit shy of the 10 percent estimated number. The ramifications of that are frightening.

We know they are there. We see them. We see them in grocery stores, shopping malls, in churches, in synagogues. They are accompanied generally by a frail elderly parents. But many of these people, unfortunately, have never been exposed to the formal system.

Community Services for the Aged with Lifelong Disabilities

So what do we do? We start where we are. If we can develop a formula, a strategy that works for those we have [already] identified, then that same formula and the same strategy can be used for what I call the "sheltered generation." Those who were born too soon...They were sheltered by their parents because there were no formal public education programs. They were sheltered in the back rooms to avoid institutionalization. They have not had an opportunity to develop the survival skills, at least those that older DD people who have been in an institution or in a community formal program have developed.

Our public policies and various support services such as those offered under the Older Americans Act require particular sensitivity to the needs and vulnerability of this sheltered generation so our two systems can respond quickly and effectively when that call comes in from a law enforcement agency [official] who says, "I've got a fifty-five year old person here. Someone tells me he is suffering from what is called Down's Syndrome. His mother just died. What do I do?"—and it is 4:00 o'clock on a Friday afternoon. This is going to happen more and more frequently, believe me. Or the mother and father will not die, but they will be in an acute care setting totally hospitalized, not ambulatory, and here is this 55 to 60 year old individual and no record of him. You do not know anything about him. You have no record of him in any formal system. He was sheltered, and is not equipped to deal in a world without protection.

The older situation is those who are not part of the sheltered generation. They **have** been exposed to

programs—either in an institution or in the community. Maybe some of them have been gainfully employed. Now these people are entitled to retire. How do we integrate them into the regular "retirement living" modality of this country? What constitutes "best practice" for this group of individuals?

When it comes to best practice in integrating our programs, best practice is what works, and what works is common sense, and common sense starts with education and allaying fears and keeping it simple. We must stress similarities, not differences. The older developmentally disabled person is more similar to than different from other elderly persons.

Two Examples of Best Practice

I am going to mention two specific projects. They are the two that I am most familiar with, and they are examples I think of "best practice."

The first is a project that was conducted in Dade County [Florida] called Project SHARP, (which stands for "Shared Day, Homebound, and Respite Program"). It was a two and one-half year project. This project worked with three groups of developmentally disabled clients. One group was currently attending a sheltered workshop at the Robert Knight Activity Center. They met the age criteria (age 55). Another group of developmentally disabled older persons [age 55 and older] was at home and was part of that sheltered generation. They had never been to a place like Robert Knight. They were with their parents who were becoming frail and elderly, and so there was an "in-reach" aspect to serve not only the client, but the client's aging parent [as well] who oftentimes needed more services than the client did. The third group was a group that was living in a home, a residential setting, a group home for older retarded people.

The Robert Knight Activity Center is almost across the street from the Jack Orr Senior Center. And the staff there got the idea that if they could take some of the developmentally disabled clients from the sheltered workshop, integrate them into the senior center operating just a block and a half away, and recruit some of the seniors who were attending that center to come over to Robert Knight and volunteer to work and augment their staff, that this would just be a wonderful cross-fertilization and a cross-mingling. And, indeed, that is what the project did. It broke down some barriers. It certainly destroyed some stereotypes and myths. And the exciting thing to me was when the federal auditor came to audit the program, she could not pick out the 6 DD clients from the 60 regular seniors who were attending the Jack Orr Senior Center, and had to ask staff to assist her in identifying [them] so she could complete her monitoring survey form.

The message I am trying to stress is that the service needs of the DD elderly are the same as the general elderly population: The difference is in the DD elderly's inability to comprehend and articulate their perception of those needs and their inability to access the needed services without help. That is really the bottom line.

Another excellent best practice effort was the Eastern Los Angeles Project for Aged Developmentally Disabled Persons. As with Project SHARP, the Eastern Los Angeles Project was funded by a combination of OHDS money, AoA money, developmental disabilities money, and other funding. It set out in a very systematic way to: define the population (which is no small task), assess their needs, define the service system and identify gaps, and determine then how to best address the gaps.

The unique part about this project was the coalition, the consortium that it pulled together to accomplish this, and it did pull together all the elements of the community dealing with the two populations.

Both of these projects identified and categorized the needs of older developmentally disabled persons. The broad catergories of needed services were found to fall into four major areas: health care, living arrangements, support services, and activity and leisure services.

Toward Integration

Before programs of integration begin, discussions need to be held with all parties involved. My experience has been that if dialogue does not occur, the automatic response, is "No, we don't want this program" or "No to that program." Often, the negative response is merely lack of understanding or fear of the unknown. Once sensitized and with a little basic understanding of the challenge at hand, I am

confident the creative juices will flow and these same professionals will become as effective enablers as they were obstacles. But we have to sell the story, we have to sell the message.

Remember, when talking about best practice, it does not have to be fancy, it does not have to be complicated, it does not have to cost a lot of money. The best practice that we as concerned professionals can practice is to keep it simple [and] use common sense.

What's Happening at the State Level: Technical Problems, Administrative Solutions

MODERATOR:

Thomas Rose / National Center on Aging and Disabilities, The University of Maryland Center on Aging

Speakers:

M. Doreen Croser / Developmental Disabilities Administration, Maryland Department of Health and Mental Hygiene

Julie Ann Jackson / California Department of Developmental Services

B. Stockton Clark / New York State Office for the Aging

Paul D. Cotten / Boswell Retardation Center, Mississippi Department of Mental Retardation

---

"Let us move toward integration and, first and foremost, let us move toward choice on behalf of the person that we are serving...so that the individual can live in the most appropriate way possible."

—Julie Ann Jackson

M. Doreen Croser reported that the Maryland State Developmental Disabilities Administration has been interested in the issue of aging for about two years. At the formal end, there are a number of things already in place. She told the audience that the Developmental Disabilities Administration is developing an interagency agreement with the State Office on Aging, is amending its plans to be sure to have the appropriate language, has been looking at regulations, and has been planning to conduct training throughout the whole state in cooperation with The University of Maryland Center on Aging. "We're doing all that, and if your state hasn't started, we'll be glad to give you some assistance and advice," she offered.

The developmental disabilities network, said Ms. Croser, has a great deal of trouble with staff turnover right now. As a means of attacking the problem, the Developmental Disabilities Administration worked with the City of Baltimore and the Manpower Agency, the Kennedy Institute, the city area agencies on aging, and other departments at the state level to train older people with limited incomes to work in the developmental disabilities provider network.

The demonstration effort trained approximately twenty individuals in a four-week training program managed by the Kennedy Institute. Out of the 15 people that completed the course, 10 are now employed in the DD provider network. Ms. Croser noted that a lot of fancy footwork had to be done to get around the regulations. "Many of our older citizens did not have high school educations," she said. "Our regulations require that. We just said, 'Look, we want to do this. It is a demonstration effort. We'll change our regulations if the project works.'...In the western part of the state where we have an unemployment problem, we are going to replicate the project there. We're going to replicate it on our eastern shore. It's a project that focuses on a need and a benefit for both groups."

As another example, Ms. Croser cited a day program run by an area agency on aging which was serving some very severely developmentally disabled people. The area agency wanted to expand the program, but needed some money to do it. The Developmental Disabilities Administration found funding to serve an additional few people. Because the area agency was not one of the DD network's provider agencies, Ms. Croser noted, the project was financed on a demonstration basis. Problems of conflicting provider restrictions seem to become reconciled or gotten around once a program is going and there is interest and a commitment to its success, Ms. Croser offered.

Julie Ann Jackson discussed some of the problems that the California Department of Developmental Services has run into with respect to integrating services for older persons with developmental

Editor's note: In August 1987, The University of Maryland Center on Aging, the Maryland Department of Health and Mental Hygiene, and the Maryland State Office on Aging were awarded funding by the U.S. Administration on Aging for a two-year project entitled "Partners in Aging and Developmental Disabilities: Focus on Day Care."

disabilities. The most problemmatic issue, she said, has been the fear on the part of area agencies on aging of "opening up the flood gates," she noted. "There is somehow or another the assumption that the DD agencies...are going to transfer their caseload to the AAAs. That is not the case. What we are finding is that there are certain services that may be appropriate and available to the older person with the developmental disability, but that doesn't mean that it is automatic that they should be served by those local programs."

Ms. Jackson said she is trying to create a new structure for adult services in California based on a philosophy of integration. In structuring services for older Americans with lifelong disabilities, "let us move toward integration, and—first and foremost—let us move towards choice on behalf of the person that we are serving," emphasized Ms. Jackson. "We tend to **place** people, rather than to **assemble services** so that the individual can live in the most appropriate way possible...If we're going to allow people to retire, how can we do it in concert with the values that we hold dear for integration of appropriate services?"...The California Department of Developmental Services has a major initiative to looking into this area," she said.

B. Stockton Clark, representing the New York State Office for the Aging, described a project undertaken jointly with the New York State Office of Mental Retardation and Developmental Disabilities called "Testing the Feasibility of Integrating Older Developmentally Disabled Adults into Aging Network Services." The project, he said, has three phases: (1) a study and analysis of barriers and recommended strategies for overcoming them, (2) field demonstration to test integration strategies, including case finding, case management and referral, integration into day care, nutrition sites and senior centers, and (3) development of "how-to" manuals to disseminate information about best practices and provide more encouragement for people to adopt these programs. "The ultimate goal of the project," Mr. Clark said, "really is to create a...fertile environment so people feel as though if they do [integrate services], they can both maintain the integrity of the program that they have and provide a welcoming, reinforcing environment for older developmentally disabled adults to come into those programs."

Paul D. Cotten described the Mississippi Department of Health's program for assisting older Americans with developmental disabilities. In 1985, he said, the department sponsored a Conference on the Elderly Mentally Handicapped Mississippian. Also at that time, state task forces were established to examine issues relating to alternative living arrangements, day services, support services, and funding and training. One of the products that was developed during that time was a glossary of terms that crosscuts both aging and developmental disabilities.

In Mississippi, functional assessments are made of individuals with developmental disabilities who are sixty or older. A determination is then made of the types of services needed (either provided through the MR system or the generic aging service system, or both). In cases where generic aging services would be beneficial, the Department of Health contributes either some money or some personnel to ensure that such services are provided, Mr. Cotten said. He noted that, "if after a period of 90 days, it's felt this person is not appropriately placed in that system, then our case manager is already involved with that person and is able to locate another kind of service for that person. So we are looking at what's appropriate for the individual and what are the choices for that particular individual." The Mississippi Department of Health, he said, provides consultative services and training for aging network agency personnel.

Part five: Strategies and Recommendations: Policies, Plans, and Programs

Strategies and Recommendations

Discussion Group I-b:

Moving Forward: Action Steps and Ideas for Advancement of Management and Administration

Discussion Leader:
John L. Stokesberry / Southeast Florida Center on Aging, Florida International University

Resource Persons
Edward F. Ansello / The University of Maryland Center on Aging
Matthew P. Janicki / New York State Office of Mental Retardation and Developmental Disabilities

Some of the major strategies that have been used or could be experimented with by states to improve management, coordination, and administration of services for older Americans with lifelong disabilities are described below:

Interagency Coordination and Communication.

- To help achieve the objective of building bridges, the two systems of aging and developmental disabilities need to get to know one another to build trust between them. Meetings between state leadership in aging and developmental disabilities/mental retardation are an excellent means of assuring effective and ongoing communication. Such meetings should not preclude the involvement of other allied systems, including state Medicaid, mental health, vocational rehabilitation, social services, and education agencies.
- Arrangements should be made by the respective leadership for informal gatherings to meet their staffs and become acquainted with each system's inner workings.
- To improve both relationships and communications, it is suggested that state aging and MR/DD agencies undertake a more intensive program of information sharing.
- The alternative to coordination is expensive duplication. To enhance coordination and cooperation between the two systems, statewide conferences focused on the intersections and joint concerns of aging and lifelong disabilities are recommended. A University or other neutral third party might host such a conference to assure a non-threatening atmosphere wherein state and local public officials, agency staffs, practitioners, researchers, and concerned citizens can engage in productive discussions for achieving common goals.
- States should make fuller use of task forces or interagency coordinating committees to provide overall policy direction and to work out specific problems of interagency cooperation.
- Interagency working agreements with specific action plans should be developed which would in turn serve as a blueprint for guiding changes in the service delivery system to meet the needs of older Americans with lifelong disabilities. To further improve coordination, it is suggested that joint budget plans be developed. Efforts at interagency cooperation can be accelerated by assigning a person who is qualified and well-liked to oversee the aging/developmental disabilities intersections.
- Agency cohesiveness and support for one another's programs in the legislative bodies of the state are very important. State aging and MR/DD organizations make powerful advocacy partners. Cross-testifying before state legislatures is especially effective as it indicates unity on an issue.
- "Public service announcements" are an excellent way to get a forum for increasing the public's interest in and awareness of the issues of aging and lifelong disabilities. Publicity will not only dramatize the needs of older Americans with lifelong disabilities to the community, but will also alert federal and state elected officials to the need for taking action.

Training and Education

- State aging and MR/DD networks have expressed the need to become more knowledgeable about each other to improve the potential for coordinating services. Cross-training of agency staffs and practitioner networks needs to be incorporated into state training plans. It is suggested that a neutral third party be used whenever possible to assume the lead role in providing the training in order to assure impartiality. States should consider the possibility of taking part in or scheduling training side by side with conferences already on the calendar.
- On the whole, funding for training and education is limited. State aging and MR/DD agencies should jointly explore ways of involving the private sector in coordinated training activities.
- Title V of the Older Americans Act (the Senior Community Service Employment Program) and the Job Training Partnership Act's 3 percent older worker set-aside are two resources that states should tap into for training older persons to work with developmentally disabled or homebound elders. States might also look to the U.S. Department of Agriculture as a potential source of training funds.

Public Policy

- The principle and practice of limiting participation in Older Americans Act programs to persons age sixty or over needs to be rethought in terms of its impact on meeting the needs of elders with lifelong disabilities who have not yet reached that age. Eligibility for essential services, such as the congregate nutrition program, should be built not on chronological age but on functional criteria.
- ICF/MR elderly are not allowed to "retire." These individuals need to be able to retire from residential day programs to participate in generic senior services. State aging and MR agencies should establish interagency task forces as a means for providing better policy direction on active treatment needs.

Advocacy/Legal Services

- Linking state aging and MR/DD advocacy services is considered essential to meeting the needs of older Americans with lifelong disabilities. Legal services are available under the Older Americans Act to **anyone** who is age 60 or above.
- Better data on who is in need of services today and in the future are needed. It is recommended that state registries be developed by the states.
- In view of the recognized importance of information and referral services in facilitating access to needed services, a more intensive program of information sharing with information and referral (I&R) systems about aging and MR/DD services should be undertaken at the state and local levels.
- Mental health agencies should be included in the coordinated services of aging and MR/DD.

Discussion Group II-b:
Service Systems Development: Strategies for the Future

Discussion Leader

Sara C. Aravanis / Center for State Action on Elder Rights, National Association of State Units on Aging

Resource Persons:

B. Stockton Clark / Program Initiatives Unit, New York State Office for the Aging

Marsha Mailick Seltzer / School of Social Work, Boston University

A variety of types of integrated and specialized community-based service arrangements are now being explored and tested in this country in response to the special requirements of older Americans with lifelong disabilities. With anticipated rises in the numbers of older developmentally disabled citizens, many imaginative new developments in the delivery of services for this population may be expected in the future. In seeking cooperative ways to better serve this population, a number of positive actions were suggested by Wingspread conferees, among them:

Shaping New Approaches

- Many grass roots service providers are working together and are doing so effectively. A great deal, however, remains to be done. In the long run, effective coordination requires that service needs of older persons with lifelong disabilities be incorporated into the state planning process.
- State plans on aging provide a framework and overall policy direction for how funds are spent at local-community levels. A recent survey of state plans on aging reported that slightly less than one-quarter of the states have given emphasis in their plans to providing services for older developmentally disabled persons. Recognizing that state and area agencies on aging have many important items on their agendas and limited resources to deal with them, more complete information on the older developmentally disabled population is needed to lay the groundwork for programs of action.
- Recognizing that all-encompassing statewide initiatives may not be feasible-at least at the outset—it is recommended that states which do want to do something in this area begin by working with a few area agencies on aging on a demonstration basis.

Aging and Disabilities Linkage: Regulatory Aspects

- It will be necessary to effect many changes in Medicaid regulations so as to facilitate and enlarge the base of community support options for developmentally disabled older Americans. More investment is needed in the expansion of social services, as opposed to a continued reliance on the medical model.
- State aging and MR/DD leaders need to jointly develop a definition of active treatment so as to enable older developmentally disabled persons' needs for assistance to be well understood. There are a variety of activities that are appropriate for elderly people with lifelong disabilities. Medicaid rules should be revised to assure that they reflect as much as possible special service needs of older Americans with lifelong disabilities.
- State aging and MR/DD agencies should review their respective case management operations and methods to work out a common strategy for determining, on an individual basis, specific needs for service.
- Service standards need to be established cooperatively by state aging and MR/DD agencies, particularly in respect to adult day care, which will have the effect of further opening up service opportunities for older people with lifelong disabilities.

Information and Education

- Information and education are particularly critical to successful coordination of aging and MR/DD services. Education must first begin with the service providers and then extend to the community at large. Area agencies on aging have expressed the need for knowing exactly what they can expect in terms of serving elders with lifelong disabilities. Well thought-through and coordinated efforts are needed at the state level to inform and assist local-community provider networks in considering integrative program opportunities.
- There are many ways to disseminate information. For example, exchanging articles in newsletters—articles that are short, constructive, and well-written—prepares people in a non-threatening way for a different kind of client group contact.
- A much needed emphasis is on bringing together professionals in the field of aging and MR/DD institutional staffs in discussion of programs relating to the well-being of older persons with lifelong disabilities who will never leave the institution. Major areas where sensitivity training is needed include: aspects of aging; ways and means to enhance the quality of life; model service programs and optimal environments.

Discussion Group III-b:

The Need for Advocacy and Public Awareness

Discussion Leader:
Elizabeth P. Rouse / The Joseph P. Kennedy, Jr. Foundation

Resource Persons:
Cathy Michaelson / National Institute on Community-Based Long Term Care, The National Council on Aging, Inc.
Thomas Rose / National Center on Aging and Disabilities, The University of Maryland Center on Aging

The need at this time is for greater public awareness and understanding of aging and lifelong disabilities issues. Informed public officials make informed decisions. Toward that end, Wingspread participants recommended the following:

Encouraging New Attitudes and Concepts about Aging and Disabilities

- State aging and MR/DD agencies should exchange views and work cooperatively to overcome negative attitudes affecting both the aged and the developmentally disabled.
- Media attention could be encouraged that would feature the **value** of both aged and developmentally disabled people and what they can bring to their communities. State aging and MR/DD agencies could jointly produce a public information brochure, a public service announcement on radio, a commentary on television, or an editorial in a newspaper—all of which could be important in changing long-held stereotypic attitudes and concepts.
- Older Americans with lifelong disabilities need to be given every opportunity to participate in the life of their communities. Work and volunteer options need to be explored in areas where they can make a meaningful contribution, such as child and adult care. Private/public sector linkages are needed in connection with opening up opportunities for constructive involvement of older developmentally disabled Americans.
- Young parents with developmentally disabled offspring are a valuable advocacy resource. It is important for them to know as much as possible about the lifespan needs of and expectations for their children. They need to speak out and inform their legislative bodies. We can make a difference for the generation of children and youth who are growing up today.
- It was recommended, too, that states work with other advocacy groups in addition to those representing aging and disabilities concerns, in facilitating service system linkages beneficial to older Americans with lifelong disabilities, such as housing and transportation.

Family Supports and Housing for Better Serving the Needs

- Encourage families with **real** support (meaning funds).
- Develop informal networks (churches, synagogues, local organizations).
- Use home-equity mortgages to provide for the mature adult offspring of aged parents when they are no longer able to care for them.
- Develop housing co-operatives where apartments are set-aside for older residents with developmental disabilities.
- Encourage investments of venture capital by private enterprise to provide rental units in community housing for older persons with developmental disabilities. Attention needs to be given to identifying alternative funding streams for providing supportive services.
- Promote integration of elders with developmental disabilities into existing retirement, life care, and continuing care communities.

Discussion Group IV-b:

Creating a New Public Policy Framework

Discussion Leader:
Colleen Wieck / Minnesota Governor's Planning Council on Developmental Disabilities

Resource Persons:
Robert M. Gettings / National Association of State Mental Retardation Program Directors, Inc.
Marilyn Moon / Public Policy Institute, American Association for Retired Persons

What should our priorities be for older Americans with lifelong disabilities? Certain broad goals which would provide a framework for public policy are discussed below:

Orientation to Individuals in MR/DD System and Congregate Delivery in Aging System

- Case management enables the brokering of supports. Case management responsibilities must be clarified at the state level; however, the lead agency determined to be responsible may depend on the individual to be served. Variations of solutions include generic case management or joint screening and intake.
- Individual needs should determine the nature of services provided. The lead agency (aging or MR/DD) should work with individuals to ascertain need, rather than merely refer to existing services. Where congregate programs are needed or available, individuals should be guided or helped to fit into them.
- The capacity of both systems may limit the range of services and choices. However, there are resources and expertise in both systems. Expertise in aging may be social supports; in developmental disabilities it may be behavior analysis and content knowledge of the disabilities. Both systems should become alert to new and emerging needs and work toward developing new forms of service.
- Individual plans should be established for clients upon their entry into the system, regardless of point of entry. Responsibility for establishing the plan should fall to the part of the system which knows most about the needs of a particular client. Such plans should also take into consideration needs for services provided by agencies other than aging or developmental disabilities, such as health.
- Some people may never enter either system. There are some people whose IQs are above 70 who may be age appropriate referrals but who do not meet the criteria of developmentally disabled. Efforts should be made jointly to identify the currently unserved population of developmentally disabled elders, including "borderline" people whose needs may be marginal. Questions of eligibility will arise, and the systems need to work cooperatively to find ways to serve such persons. Special advocacy in their behalf will be needed to prevent them from being put in a state of limbo.
- State aging plans should give recognition to the estate planning needs of aging parents of mature adult offspring with developmental disabilities.

Medicaid Policy

- The goal of efforts by state aging and MR/DD agencies should be to try to re-orient the current Medicaid system so that it supports families. An array of community services are needed as alternatives to institutional care.
- At the national and state levels, advocacy groups from both the aging and MR/DD networks can band together to gain support for Medicaid reform which reverses the bias toward institutions.
- States which have successfully implemented programs under the home and community-based waiver should be allowed to convert to a state plan option, rather than be required to reapply.
- Efforts to bring about a national long-term care insurance program should be endorsed.

Support Individuals, Not Service Settings

- The term "array of services" should be used in place of "continuum of services" because many clients perceive of a continuum as a series of rigid steps they must take progressively in order to get the services they need and want. Individuals

should not have to earn their way through a continuum of services.

- The concept of "aging in place," as used by the aging network, should be adopted by the MR/DD system. The concept speaks to keeping clients in familiar surroundings as long as possible, altering their environments favorably, rather than moving them from facility to facility.
- Both systems should seek to adopt, use, and reinforce the principle that funding should follow the client, rather than following the various programs of service.
- Families need reorientation from placements. Staff need training to assess, plan, and broker services that meet individual needs and life choices.
- Aging resources can assist people with disabilities to be connected with the community—to make friends and to have relationships.

Quality and Personnel Issues

- A different type of management is needed in a dispersed community service system. Management styles must change at the state, substate, provider, and family levels. Management assistance must be available. The principle of "management by need, rather than by rules" should be adopted by all involved.
- Individuals with disabilities must be given the opportunity to speak for themselves. Training may be necessary. Improved self-advocacy in combination with responsive management will do much to enhance the quality of services provided.
- Personnel exchanges and/or transfers between MR/DD agencies and aging network agencies should be encouraged.
- Family members, friends, and advocates of older individuals with lifelong disabilities should be educated to recognize good or bad management practices as a means of controlling and improving services.
- Standards related to outcomes of services should be established and tied in with funding.
- Training opportunities for paraprofessionals, family caregivers, and other care providers should be expanded.
- Individuals and families must be given a role in the monitoring of service provision. The role of third party providers in assuring quality of service should be studied.

Means Testing

- Problems and issues attendant upon means testing of clients served by both the aging and MR/DD networks should be examined thoroughly.
- Further discussion and study are needed regarding asset levels and impoverishment as related to Medicaid.
- Problems and issues surrounding the growing use of private trust funds and the effect upon client eligibility for services should be studied. How can the limited assets of older persons with developmental disabilities be protected?
- Services should be affordable, accessible, but not necessarily free. Further study is needed regarding the effects of cost-sharing.

National Policies on Housing and Transportation

- The Coalition for Citizens with Developmental Disabilities should work with the aging network on policies regarding housing, transportation, and reform of Medicaid and Medicare.

Conclusion: Public Policy Implications

Janet Pisaneschi

Federal Legislation and Strategies for the Future: A View from the Senate

FOREWORD

This paper focuses on recent policy changes in the Older Americans Act that address the needs of individuals with disabilities, and on the value of coalitions as the central organizing principle for "strengthening the causes that we are trying to champion." The author shows that by working together, proponents of the elderly and persons who have endured lifelong disabilities can have a sizeable impact on the formulation of national policy. Dr. Pisaneschi is a Kellogg Foundation health policy fellow serving in the Health Office of the Senate Committee on Labor and Human Resources, U.S. Senate.

1987 Older Americans Act Reauthorization

Positive Steps to Meet Needs of Individuals with Lifelong Disabilities

The Senate's version of the Older Americans Act reauthorization legislation as it relates to the elderly with disabilities represents some compromising. Under the jurisdiction of the Subcommittee on Aging in the Committee on Labor and Human Resources, the bill will contain some amendments that address the needs of individuals with disabilities. However, it will not include everything that various advocacy groups had hoped would be included. Some compromises were necessary, as always, in order for us to at least gain an entree into the Older Americans Act legislation.

Throughout the Senate's proposed bill, the geriatric term "disabilities" is used where it is appropriate, of course, rather than listing or specifying specific disabilities (for example, the mentally retarded or even developmental disabilities). The proposed bill includes the definition of "disability" and "severe disability" contained in the Developmental Disabilities Act, thereby clearly indicating the populations addressed in the various amendments.

The significant point is that the elderly disabled and their needs will in a much larger way than ever before be acknowledged in the act.

A number of other amendments of an administrative nature form part of this acknowledgement. In the proposed bill, the Commissioner on Aging would be required to consult with national organizations representing individuals, including the elderly, who have disabilities. The Commissioner would also be required in the consultation role to develop and disseminate information on population characteristics and needs, and provide technical assistance to state and area agencies that would enable and encourage them to provide services to elderly disabled individuals in collaboration with other appropriate agencies. There is a real push, at least in this one section, that more cooperative activities take place for the disabled elderly in the states and by the area agencies.

The proposed bill also adds the Administration on Developmental Disabilities and the Alcohol, Drug Abuse, and Mental Health Administration to the list of agencies with which the Commissioner must develop planning linkages. In addition, the bill adds the Alcohol, Drug Abuse, and Mental Health Services Block Grant, the Rehabilitation Act of 1973, and the Developmental Disabilities and Human Rights Act to the list of programs which are related to the purposes of the Older Americans Act. These changes, although seemingly minor, do assert the growing presence and the needs of the elderly with disabilities in the Older Americans Act.

There are two other administrative changes which are perhaps tangential to the specific concerns of the elderly with disabilities but which may be of interest. First, the meaning of the term "health" is re-expressed in the bill to include **mental health.** Second, the bill requires that the Commissioner annually collect various data on, for example, expenditures by service category, numbers served by service category and the like. It requires that the Commissioner compile information about the extent

Editor's Note: In November 1987, the conference report on the Older Americans Act Amendments of 1987 passed the House and the Senate and was sent to the president for his signature.

to which the various centers provide the types of services required by the act, and also that they are providing services to the various populations designated in the act.

In addition to these administrative amendments, there are a number of programmatic changes that are being proposed. Several of these are changes that are a part of a larger change that is being proposed in the Ombudsman Program of the act. In general, the Senate version will strengthen the requirements of the Ombudsman Program at the state level. It requires that the state plans include the establishment and operation of an Office of Long-Term Care Ombudsman. Some states are already doing this. The bill now requires it for all states.

In addition, the state agency is to establish a toll-free hotline to facilitate communication of complaints to the ombudsman. It also requires the Commissioner to provide an annual report to the Congress on the ombudsman services provided by the states and the problems and current issues that emerge from the states' reports concerning their ombudsman programs. Issues related to quality of care and resident rights are to be specially noted in these reports. Finally, the bill also would require that the Commissioner conduct a study concerning both the ombudsman's activities in behalf of residents of board and care and similar facilities, [and] the effectiveness of recruiting, supervising, and retaining volunteer ombudsmen.

More pertinent is the provision that requires state agencies to coordinate ombudsman services with the protection and advocacy systems for individuals with developmental disabilities and mental illness. Further, the Senate bill would authorize the Commissioner to make grants to not less than three [but not to exceed] ten states to demonstrate and evaluate cooperative projects between the state long-term care ombudsman program and the state protection and advocacy systems. One million dollars for each of the fiscal years 1988 and 1989 are authorized for these [demonstration projects] specifically in the legislation.

The purpose statement of the demonstration, education, and training projects section of the act will be changed to add emphasis for demonstrations on minority individuals, low-income individuals, frail individuals, and individuals with disabilities. The amendment also adds to the list of health care projects to be given special consideration—those projects that serve elderly individuals with speech, language, and/or hearing disorders. It would also specifically authorize grants or contracts for the development of training programs for service providers under Title III and nursing home care providers to meet the special needs of older Americans with disabilities who are residing either in the community or in nursing care facilities. Also we were able to get the inclusion of disabilities in the list of areas on which a special emphasis gerontology center may concentrate. [Even though this amendment is not as significant a change as we had hoped,] at least we have gotten our foot in the door.

One other final amendment that is included in the Senate bill would make individuals with disabilities who reside with and accompany their guardian or their parents to congregate meals to be eligible to participate in the congregate meals program.

The Aged and Public Policy

I am truly overwhelmed by the [policy] context in which the elderly must be placed—the overall context of health care and also the overall context of social services. Even Senator Kennedy's legislative initiatives alone, precluding all the other health care initiatives that have been developed, bespeak the vast array of our nation's health care needs: catastrophic illness protection for the elderly and disabled; protection for the uninsured; infant, child, and maternal health needs; AIDS research and treatment. And there are others in addition to the Senator's initiatives: protection against spousal impoverishment; long-term care needs which are related to spousal impoverishment; assistance for Alzheimer's victims; and others.

Each of these issues has faces—countable faces. None of us can ignore, for example, the frightening projections of AIDS infection and death and the specific people that AIDS victimizes. None of us can ignore those in our nation and in our world. And who of us can be less than embarrassed, and I hope disturbed, that our nation ranks seventeenth in the world in infant mortality rate, behind Singapore and Hong Kong? And who of us can forget the 37 million uninsured Americans—and it grows a million a year—who, as Senator Kennedy described them, "are

tragedies waiting to happen?" And who of us, too, can escape the reality of the growing numbers of our nation's elderly citizens who must become paupers in order to obtain care?

How can any of us who want to have hope for a future of promise, or who want to continue to respect and show gratitude for our past, deny or disparage the claims of any of these groups, of any of these needy fellow Americans? Yet to recognize these claims or to assume this challenge, the likes of which perhaps we have never before faced, is awesome indeed.

It is a tough time for idealists such as me. I want everyone to have his or her due, but the price tags on these needs are not K-Mart or Dollar General Store variety. Yet I want to believe that we can somehow provide some solution to meet at least some needs, to ease at least some pain. Perhaps we cannot achieve the meeting of everyone's wants or the meeting of everyone's needs, but we can achieve some of those. To do so, however, I believe we must certainly work together.

Coalition Building

We must have more coalitions. We must have more working together. I think it is important for us to begin this coalition forming to minimize the competitive, perhaps even sometimes viscious, battles that can ensue if we do not, and somehow in our coalitions to actually strengthen the causes that we are trying to champion.

On a very practical note, coalitions are very helpful for [congressional] staff. For example, [as] the Alcohol, Drug Abuse, and Mental Health bill [has moved through committee], it has been very helpful to work with a mental health coalition, rather than have to work with the seven or eight or nine different associations. They did their homework before they came to us, and their arguments become even more persuasive. It is not just one particular association speaking—it is a number of associations speaking. What they say carries more weight. We are rather relieved because it lessens our need to have to play peace-maker and negotiate.

"Usually coalition forming necessitates the gathering of information. Coalitions have all their ducks in a row oftentimes. It is very helpful to staff and ultimately then to the Congress."

Usually coalition forming necessitates the gathering of information. Coalitions have all their ducks in a row oftentimes. It is very helpful to staff and ultimately to the Congress. Both on theoretical and very practical levels, legislatively the coalitions are imperative.

The best case that anyone can make is the specific case. When you are trying to really sell an issue, Congress needs to see the faces of the people you are advocating for. We need to know the stories that you know personally and first-hand. We get constituency mail, but sometimes the people who need the help cannot write the letters. They cannot describe their case to us. And I think it is the responsibility and the challenge of advocates for these groups, especially the elderly with disabilities and other groups, to make the case. One of the ideal ways of making the case is to present the specific cases. They win arguments often.

The general data, the overall impact data, are very important and essential. But I would encourage you to develop those case studies of those real live persons who are suffering as the consequence of needs. Make those cases now. I think it will convince people more of the essentialness of the goals which you are seeking and the values that you are really proponents for.

And even though your crisis may be down the road, now is the important time to plan so you can possibly avert that crisis.

Robert M. Gettings

A National Agenda for the Future: Action Steps and Recommendations

FOREWORD

What line of action will produce the best possible results for older persons with lifelong disabilities from the resources available? As the author points out, there are "some points of very significant agreement" on which the two systems of aging and developmental disabilities have to build. The first is based on a commitment to home and community-based care, the second on early intervention and prevention of debilitating conditions, the third on raising the basic support level under SSI, the fourth on providing affordable and decent housing for every American, the fifth on developing coordinated transportation systems, and the sixth on civil rights. Robert M. Gettings is executive director of the National Association of State Mental Retardation Program Directors, Inc.

Restructuring of Long-Term Care Policy

Long-term care does not necessarily begin and end with Medicaid. I would urge that we think holistically about the problem. I do not think the answer to long-term care reform is to deal categorically with the needs of the older developmentally disabled. We have to think about long-term care for frail elderly persons and long-term care reform in terms of the overall developmental disabilities population.

There are some points of very significant agreement which we have to build on. Among those is the notion that home and community-based services should be the starting point for how we deal with people who have long-term care disabilities and chronic health and social care needs. Where we should start and the whole notion of institutional bias as it occurs in current policy is something that should be the major focal point of any kind of reform strategy.

Second, we cannot continue to ignore early intervention and prevention of debilitating conditions that pose significant major problems into the future. We often forget, or overlook, the consequences of our early failure to do anything that leads to those kinds of disabilities. The United States is seventeenth in the world in terms of infant mortality and morbidity. That has natural consequences in terms of what we later deal with in our agencies. Initiatives, for example, under Medicaid to expand services to low-income pregnant women and infants are very important in terms of what we will be dealing with in the decades ahead.

Third, basing public policy on **dependency** as the core defining characteristic of persons who need services needs to be re-evaluated. In other words, the way in which Medicaid public policy currently works is: if I have a client who is Medicaid eligible and I continue to provide a service to him that is a care-oriented service, then I will continue to be funded. If I find a way of making him less dependent, I will be rewarded by losing Medicaid eligibility on that individual's part. If I want to provide a day service to a 24 year old developmentally disabled adult in the community or in an institutional setting, I can do it forever and Medicaid will pay for it. As soon as I start making that person less dependent on society and able to earn his own way, Medicaid will say to me: "We no longer can support that kind of service." There is something wrong with that.

We as an association, in collaboration with other organizations that are members of the consortium concerned with developmental disabilities, will be seeking in this Congress to get several amendments included. One of those relates to the case management coverage. We are looking for some language that clarifies [the Health Care Financing Administration's interpretation of the states' obligation to observe freedom of choice in the delivery of case management services]. I say to my friends at HCFA, "What you are proposing is 'information and referral' services, not case management services." Case management assumes that there is a designated person within a catchment area—a designated agency that has responsibility. And HCFA is telling states that it will not permit them to cover case management services if they violate that freedom of choice.

Still another issue is the inappropriate placement of developmentally disabled persons in nursing homes. The General Accounting Office just completed a study on nursing home placements on

behalf of the mentally retarded in the three New England states. GAO concluded that there are possibly 140 thousand mentally retarded individuals in general purpose geriatric nursing homes in this country, most of them placed there for fiscal expediency. In most state systems, nursing home payment levels are so low that you cannot justify an appropriate community program alternative and still make it cost-effective within the context of the home and community care waiver. What we are proposing is that states, on behalf of those clients who are found to have active treatment needs that otherwise would require placement in an ICF/MR facility, be able to use their average per capita costs for ICF/MR services in developing the cost comparison for home and community care waiver services. I think more states would be willing and able to use the waiver for that purpose if they had that authority.

Last year, Congress removed authority for the Secretary to waive parental and spouse deeming as part of a home and community care waiver. We are seeking language that would restore the authority to waive deeming under a home and community care authority. Deeming is the process by which you attribute the income and resources of the family to the individual who is receiving services. If you do that on behalf of a middle-class family where the child lives at home, you in essence remove their eligibility for Medicaid services. Similarly in terms of a spouse who may otherwise be eligible...

In the longer term, I think it is important that we put out before people strategies even if they do not prove to be immediately legislatively feasible so that we have something out in front of us, a framework, a structure so that when we are forced to move incrementally, we know the direction in which we want to go.

There are points of disagreement.

In terms of covering long-term care services, [some espouse] a social insurance approach, building on the notion of Social Security to finance long-term care services. [Others think we should] use a means tested approach, building on the model of public assistance or Medicaid to do it. There are some significant cost implications to that. It will be expensive in either case. Means testing is the less expensive of the approaches, but you run the risk of the so-called "notch" problem that you involve in social policy, which is: If you are just slightly above the income eligibility level, suddenly you fall off the cliff and there are no benefits available to you. If you use the social insurance approach, you obviously achieve equity across the entire population, [but is America] prepared to finance that? Every other western European country, modern democracy has said yes to that question; thus far, we have said no. But it is a very basic consideration in terms of long-term care policy.

Income Maintenance Policy

Opportunities to retain income benefits that are now available permanently on behalf of SSI recipients ought to be extended to Social Security Disability Income (SSDI) recipients.

Another issue from the point of view of the elderly community is to lift or at least raise the current restriction on earned income disregards for elderly persons. It has not been shifted to my knowledge in the past ten years. It is time that that was adjusted or, hopefully, removed.

We also need to think about raising the basic support level under SSI up to the poverty level. That is another possible agenda item.

National Housing Policy: A Reconsideration

I think it is time that we thought through the question: Are there ways in which the federal government can provide the states incentives to cover extraordinary housing needs of persons who are either elderly poor or disabled and poor through the SSI mechanisms? Perhaps there can be some type of a matching arrangement above the basic federal support level that rewards those states that have a supplementation schedule.

Congress passed a basic housing law in 1949, the goal of which was to provide affordable and decent housing for every American. We are now closing in on 40 years later, and we are further away from that goal than we were at the time that President Truman signed that bill into law. In fact, over the last seven years, federal obligations for housing assistance programs have dropped from about $30 billion a year down to around $7 billion, according to the president's budget this year. I think some of that will be restored, maybe up to $10 million, but still we will have a third of the annual expenditures on housing through the federal government than we had at the

beginning of the Reagan administration. No program in the federal government has been as devastated by the Reagan administration as housing. [It is a policy area] that we definitely have to work on.

One of the big issues is construction vs. subsidy of housing. A program that we share an interest in is the Section 202 Housing Loans for the Elderly and Handicapped construction program. I have grave reservations about the program. I do not know that it is the wisest use of limited federal resources. Local non-profit organizations that are fairly sophisticated and flexible tend to qualify for very large federal loans to construct limited housing for people. I wonder if we use that same amount of money and then spread it out, whether we can get more leverage from it.

Transportation

Transportation is another area that has been heavily hit by federal cutbacks. Local mass transit plans are now being developed. Local transit agencies, in order to qualify for UMTA [Urban Mass Transit Act] support, have to provide a plan for transportation for the elderly and handicapped. I do not think we have been active enough in terms of trying to influence those plans in many states and localities.

DOT's [Department of Transportation] regulations have some very serious problems as far as [UMTA] is concerned. For example, they ignore the mentally disabled entirely. In other words, handicapped users of transportation are **physically** handicapped users of transportation. The other problem is that they set a dollar ceiling, a percentage ceiling, on how much a local mass transit authority has to expend in order to meet its obligations [now set at 3 percent]. There are some amendments that will be introduced shortly by Senator Cranston to try to deal with that.

The whole question of developing coordinated transportation systems at the local level for elderly and handicapped persons is one that I think needs a lot more attention.

Civil Rights

We have gone through a period where it has been very difficult to talk about civil rights of people. But this year, I think there is a great deal more hope that we will be able to get a civil rights bill through as far as restoration of civil rights on a broad scale. There is legislation now pending that Senator Kennedy is sponsoring; I think there is a fairly good chance that it will pass. Another bill that is going to be heard this year is the Civil Fair Housing Amendments. Essentially what that will do will be to put in place an administrative device for hearing complaints about violations of persons' fair housing rights [to protect] people who cannot afford to go through the expense of litigation. There are also some specific protections in terms of zoning for group homes and other kinds or residences for the handicapped.

Concluding Comment

I think there is a very major agenda ahead of us. Much of that agenda from a national perspective I think is to re-energize ourselves and begin to ask what is it that the federal government ought to be doing in this area, rather than fighting a defensive battle all over again.

Donna McDowell

National Policy Goals for Older Persons with Developmental Disabilities

FOREWORD

Donna McDowell in characterizing America's public policy goals for the elderly contends that the same goals apply to older citizens with lifelong disabilities. She states, "The aging and developmental disabilities networks are obliged...by their public mission to make a common cause of the interests of older persons with lifelong disabilities at the federal and state level." Ms. McDowell, director of the Wisconsin Bureau on Aging, is second vice president of the National Association of State Units on Aging.

Part of what is difficult about deciding on policy goals for the elderly persons who have developmental disabilities is that we are not really clear about our policy goals for the elderly, period. I have come to characterize our policy goals for the elderly in three sometimes contradictory ways:

1. To enable older persons to **hang on to what they've got**—a home, a lifestyle, lifetime savings, family, and social relationships.

2. To have, to be given, or have recognized a **special status** in the family, in the community, and the nation as the "elders of the tribe"—persons who have made lifelong contributions and who have survived the challenges of life to become its veterans.
3. To entitle persons with the physical, psychological, and economic insults of old age to the benefits of the welfare state, benefits predominantly based on **need** (not age), but also tailored to the special circumstances of old age.

This Conference has, as all good conferences do, taught us ageniks that we still have a lot to learn about the diversity of the aging population and the uniqueness of each older citizen. Most of us have overlooked the special quality of aged persons with lifelong disabilities. Upon some reflection, then, I would propose that for older persons with developmental disabilities my broad policy goals are still applicable:

1. Older persons with developmental disabilities ought to be able to **hang on to what they've got**—knowledge and skills painstakingly acquired, physical health, social relationships, a place (perhaps only a very recent place) in the community.
2. Older persons with developmental disabilities deserve a **special status** in the family, the community, and the nation—**truly** as survivors, as veterans of life who have too often experienced the harshest and most crippling experiences of life: rejection, neglect, denial of opportunity, incarceration, restriction of the rights and dignities of adulthood. Yet these survivors often shame us with their generosity, good humor, joy in the small pleasures of life.
3. Older persons with developmental disabilities will be most likely to suffer the insults of old age: ill health, loss of family, mental impairment, economic dependency, and these entitle them to public benefits. Their needs, too, should be met with **special consideration for their age and for the achievement of long life.**

The Aging and Developmental Disabilities Partnership

The aging and developmental disabilities networks are obliged, I believe, by their public mission to make a common cause of the interests of older persons with lifelong disabilities at the federal and state level.

What Is to Be Done?

The federal Older Americans Act and the Developmental Disabilities legislation should both reflect in common terms the public responsibility of the two networks to the older developmentally disabled populations. We need to seek jointly or concurrently **access to service resources which alter the bias toward institutional funding.** These resources should include the categorical service funds needed to support program development, advocacy, and protection. And we should **restructure the entitlements to address their institutional bias.**

In Wisconsin, the imbalance in institutional vs. community funding in longterm care for all populations is about 3-to-1, that is, we spend about three dollars on institutional care for every dollar we spend in the community. For the **elderly,** however, we spend about ten dollars in institutions for every one dollar we spend in the community. The ratio of imbalance is about ten-to-one for the elderly vs. three-to-one for all populations. That's an important piece of information for us to be conveying to our state legislatures and to our congressional delegation when they ask why it is we want to go to all this trouble of restructuring Medicaid. Clearly, making the Medicaid waiver program an optional benefit in the state Medicaid plan is an important element in this strategy.

I have discovered that lawmakers need a great deal of educating to understand that **quality assurance** is entirely dependent on the adequacy of assessment, case planning, and case management, that these are essential services that have more to do with quality and outcome of services than with cost containment, although cost containment may be a by-product.

Capitated funding mechanisms with maximum flexibility in their purchasing power are also essential to cost-effective, high quality services. It has been my experience, and in recently testifying on the Older Americans Act, that there is a lot of interest in Congress in the issues of quality assurance. But even on the committees with authorizing authority for the Older Americans Act, terms like case management are absolutely foreign. They do not know what it means. They do not

know what it does.

Long-term care is, along with health care costs in general, the **major** public policy issue in the field of aging. While we make here common cause in Medicaid for a balanced, flexible funding source for the poor, the DD advocates among us need to appreciate the goal of many aging advocates for a universal social insurance program for long-term care which is financed on an ability to pay basis, but which does not require impoverishment to qualify.

Clearly, we all have a common interest in SSI, in taking all of our elders out of poverty. I hope that our DD allies in this effort can come to appreciate our concern about the asset limit which was not adjusted to inflation for a whole decade. Just as disabled folks cling to a few valued possessions for many years—a radio, a picture, a trophy, something that they've earned, something that they've owned—so, too, do the elderly poor cling to a nest egg of savings accumulated over sixty years—a nest egg which may prevent their qualifying for SSI. These nest eggs are a kind of trophy which says: I worked, I was prudent, I was thrifty, I saved, I will not die a pauper. Very poor older people will live on very modest incomes and not apply for SSI in order to protect a $4 thousand or $5 thousand pass book account which they will never touch.

"Just as disabled folks cling to a few valued possessions for many years—a radio, a picture, a trophy, something that they've earned, something that they've owned—so, too, do the elderly poor cling to a nest egg of savings accumulated over sixty years—a nest egg which may prevent their qualifying for SSI. These nest eggs are a kind of trophy which says: I worked, I was prudent, I was thrifty, I saved, I will not die a pauper."

Perhaps we should think about that nest egg or lack of nest egg, not only for older people in general, but also for older developmentally disabled persons. To what extent does an older developmentally disabled person have tangible, material evidence of a lifetime of conforming to society's expectations?

Perhaps through employment programs JTPA, the Title V supported work programs—we can create jobs and earnings for folks who can thereby acquire possessions of lasting value and meaning for them. That means engaging the interest of Title V national contractors like the National Council on the Aging, Inc. The National Association of State Units on Aging and many state units are also very involved in employment programs. Perhaps, too, we can use our legal services and our advocacy systems to enable elderly parents of the disabled to pass on an inheritance which does not undermine their disabled adult offspring's eligibility for entitlements. The ability to leave a personal legacy, to leave your mark, is a strong human ambition that should not be denied to the disabled or any elder. But I am not sure it is opportunity we offer disabled older adults.

The aging network has a strong interest in family caregivers. Family caregivers are often spouses, sometimes adult children, perhaps aging parents of a disabled child. They are usually women. We would like our DD allies to join us in our effort to get recognition and relief for caregivers. We tried to get this recognition in the current reauthorization of the Older Americans Act; we have not done it yet.

Initiatives across the country to address the effects of Alzheimer's and related dementias have engaged the aging network in organizing respite, support groups, and caregiver training. I think the aging network has a clear opportunity and responsibility, whether or not it is in the Older Americans Act, to assist the elderly parents of disabled adult children. Here in the issues of family support I think it is important that we break down categorical barriers and unify our efforts to create support for family caregivers.

Value and Meaning from Childhood and throughout Life

Our job is to help older persons get access to human services, including services for the developmentally disabled. And our job is to build or to retool programs and delivery systems that have not existed or have not been responsive to older persons.

I would like to propose that federal ACTION legislation require an opportunity for elders with mental retardation or developmental disabilities to play an **adult** role in intergenerational programs, programs with both disabled and non-disabled

children.

I really believe that tomorrow's world can only be better if today's children have developed relationships with disabled adults, as well as with older adults who do not have disabilities. We are talking about altering public perceptions. We have to begin to do it very early, and I think the ACTION legislation is a place to require that some programs develop.

If you think about it, disabled adults are denied a lot of opportunities by society, but if you look specifically at older disabled adults, they are denied by their life circumstances the opportunity to be a grandparent, a great-aunt, or a great-uncle. So perhaps we need a new variation on Foster Grandparents where the grandparent is disabled.

I would like to close with a story. The story is Katherine's. Katherine is seventy-two years old. About the age of 10 or 12 she was labeled "simple-minded" and sent to a state training school. She lived for 60 years in institutions of various sorts, ending up in Madison's Allen Hall, a large residential facility right next to the [University of Wisconsin] campus.

When the operators of this facility decided to close because they could not get Medicaid anymore, in 1982 Katherine was placed by the county social services department in an unusual foster home. The other three residents were small children, and the provider was an older woman. That home was also the setting for a family day care for another three children. Katherine isolated herself in her room for several months after moving into this foster home...didn't communicate...didn't look after herself except with very specific instructions.

And then in July of 1983 a newborn infant was placed in that foster home; her mother was in prison. The foster mother told Katherine that she would just have to come out of her room and help with the baby. Katherine was going to have to assume some responsibility around the house. Her responsibility was to look after the baby whose name was Desiree.

Katherine held, fed, and changed the baby Desiree. In the chaos of this wonderful but very chaotic household, Desiree received Katherine's constant attention, affection, and physical contact, instead of what I believe would have been the alternative of spending her infancy alone in a crib or a playpan.

Desiree's mother was paroled and almost immediately ran away. And so, at the age of fifteen months, Desiree was placed in a new foster home where the parents were willing and able to adopt her. She is today a beautiful, bright, and active child whose coloring reflects her American Indian heritage, and whose emotional stability reflects the bonding, affection, and the physical contact she had in infancy from Katherine. A **throw away child** was held and protected by a **throw away adult** until the child could find a permanent place in life.

We have been talking around the issue here of—"Can older persons with developmental disabilities make a contribution? Can they leave a legacy?"

Katherine did.

And since Desiree, now known as Jesse, is my daughter, I am grateful to Katherine for her legacy and for her gift to me of a child intact.

Wingspread — An Epilogue

Matthew P. Janicki and Edward F. Ansello

On November 29, 1987 President Reagan signed into law the Older Americans Act Amendments of 1987 (now Public Law 100-174). Earlier he had signed into law the Developmental Disabilities Act Amendments of 1987 (now Public Law 100-146). Both of these statutes contain provisions related to aging and individuals with developmental disabilities. A number of far-reaching and important provisions, as noted by Janet Pisaneschi in her comments at Wingspread, had been recommended for inclusion in the Senate versions of both bills. Over the fall, the conference committee process ironed out differences between the House and Senate versions, with the House acceding to most of the Senate provisions. The provisions that survived are significant and should have a profound impact on the means with which states can individually and collectively work to develop and provide services.

The key aging-related amendments to the Developmental Disabilities Act include the requirement that the developmental disabilities planning councils review and comment on the state aging plan (prepared by the state's unit on aging); that the state unit on aging's administrator be included as a member of the state's developmental disabilities planning council; and that funding be provided so that the Administration on Developmental Disabilities can set up a number of university-based aging and developmental disabilities training centers. The explicit purpose of these university programs is to become technical resource centers and to cross-train staff already working in either the mental retardation/developmental disabilities or the aging-related systems.

More dramatically, a key disability-related amendment to the Older Americans Act includes specific language calling for the inclusion of "individuals with disabilities" in all facets of the Act's services. Other provisions include the following: **At the federal level** the Commissioner of the Administration on Aging (AoA) is required to consult and collaborate with the Administration on Developmental Disabilities; to consult with organizations representing the interests of older individuals with disabilities in evaluating the impact of the AoA program; and to designate a university-based multi-disciplinary center with a focus on disability.

At the state level, state aging and mental retardation/developmental disabilities agencies are encouraged to plan and develop services cooperatively for older individuals with developmental disabilities; and among other things, support is to be provided for the adapting of homes of older persons with disabilities. **At the local level**, disabled, dependent adults under the age of 60 can now be served at congregate meal sites together with their parents or caregivers, and assistance is to be given to prevent unnecessary institutionalization of disabled elders and to aid those disabled elders currently institutionalized who wish to return to community settings.

What Are States Doing?

As a follow-up to the June, 1987 Wingspread meetings, John Stokesberry and his colleagues at Florida International University conducted an informal survey of states to determine what activities were being undertaken or planned across aging and disability agencies. He found that a number of states were planning aging and disabilities conferences or statewide meetings, developing interagency committees or agreements, exchanging training resources, funding university research projects, requesting attention to the issue by state developmental disabilities planning councils, or holding regular meetings or discussions among aging and disability agency counterparts.

It is obvious that the convening of key state aging and lifelong disability leaders at Wingspread has had an effect. In those states where activities were already begun, the dissemination of information to other participants helped focus attention on the projects and share technical expertise. In those states where special initiatives were not yet undertaken, the information sharing at Wingspread has helped stimulate new ideas on what could be done. All in all, the convening stimulated attention on the issue of aging among individuals with lifelong disabilities.

Yet To Be Done

What remains to be done? For those of us involved in administration, training, program development or family services responsibilities, what options are

open to us to bridge our efforts across the aging and disability networks? Although neither network is financially well-endowed, both provide services and programs that can become the focus of shared initiatives. For example, senior centers, day care, and congregate meal sites are excellent settings for socialization, learning new skills, and enabling disabled elders to feel part of the community. These sites have yet to be fully utilized as locations where older individuals with disabilities can become mainstream users.

We can also undertake steps to aid individuals and families in the following situations. Increased longevity among adults with developmental disabilities has created a demand for services and special attention that many localities are ill-prepared to address. While many have developed child-oriented developmental and remedial education services, as well as adult-oriented vocational and social developmental services, the new demand for senior-oriented retirement services has been, in many instances, unanticipated. Further, mental retardation policy makers and administrators themselves are undecided as to whether to create a parallel senior services track within mental retardation services or to collaborate with the aging network in the use of existing or augmented senior services within that network.

In some situations, increased longevity has resulted in unusual demands. For example, older persons with Down's syndrome may experience both premature aging and Alzheimer's disease, thereby challenging agencies to develop services to accommodate middle-aged adults who are aging prematurely and/or who are experiencing progressive mental debilitation.

Other problems relate to transitions. For older adults with lifelong disabilities, transition-related problems include the aging of parents that results in the two-generation-geriatric family, growing older or "aging in place" in a community residential setting, and the challenge of successful retirement from a vocational or developmental activity.

In the instance of those older individuals living with their families, a number of problems arise. One is the reality that, unlike most elderly persons, older mentally retarded adults generally do not have children or a spouse on whom they can depend for support. In some cases, they live with very old parents who still provide for their day-to-day supports. In other instances, it is siblings or the children of siblings who provide care, and they may be ill-prepared to provide extended support given the competing demands of their own spouse and children.

"Aging in place" of older adults currently living in a variety of community residential situations (such as group homes, board and care homes, foster family care homes, supportive apartments, and the like) is another problem area. To prevent unnecessary institutionalization, consideration has to be given to either re-arranging the types of services provided as these residents age or providing for a broader range of community support services. Such "aging in place" can also occur in a variety of institutional settings, presenting yet another set of problems.

Most vexing is the situation of those older mentally retarded persons who need retirement-oriented senior programs in lieu of their current vocational involvement. It is easy to effect "retirement from," but it is not so easy to effect "retirement to." Confounding this are current federal rules and regulations in the Medicaid program that are only beginning to recognize the differing demands of age upon program requirements.

What Resources Can Aid Us?

What technical resources have evolved since the Wingspread meetings? We are seeing more university affiliated programs developing their expertise in this area, particularly with the infusion of new funds from the Administration on Developmental Disabilities for training and education related to aging. We are seeing the Administration on Aging funding demonstration projects directed toward increasing community and aging network awareness. We are seeing Geriatric Education Centers and various centers on aging or gerontology awaken to the professional community's interest in the service populations of individuals with lifelong, as well as later life, disabilities. We are also seeing states investing valuable resources to develop pre- and in-service staff training curricula that can be used by both systems.

We have begun to see more state aging and mental retardation agencies jointly responding to common

interests through interagency agreements, co-sponsored demonstrations, training, exchanges of personnel and information. We are also witnessing the emergence of the research community rising to the challenges of aging among individuals with mental retardation. Both the National Institute for Mental Health and the National Institute on Aging have developed applied research programs in this area, and the National Institute for Child Health and Human Development is supporting basic research on the association between premature aging and Down's syndrome.

Clearly the Stokesberry survey supports the premise that states can manage this issue of aging and developmental disabilities and can successfully anticipate the demands that future demographic shifts will bring to bear. As the recent comprehensive report of the National Institute on Aging, **Personnel for Health Needs of the Elderly**, has noted, the nation needs to shift its resources over the next thirty years to accommodate the realities of an increasingly elderly population. With the expectation that one in five Americans will soon be an elderly person, ignoring this future would be irresponsible.

In retrospect, it is obvious that the Wingspread experience reinforced those states that were already starting to respond to the changes in their populations, and encouraged others that had not yet begun to do so. We expect that the new amendments to the Older Americans Act will become the vehicle for even greater interagency coordination and cooperation. The Wingspread conference raised the issues, the Congress has provided the means, and now it is up to the states to build the bridges toward partnership. We hope that this book is a tool.

Further Reading

Books

Aging and Developmental Disabilities: Issues and Approaches by Matthew P. Janicki and H.M. Wisniewski (eds.). Baltimore, MD: Paul H. Brookes Publishing Co., 1985.

Aging and Mental Retardation: Extending the Continuum by Marsha Seltzer and Marty Krauss. AAMD Monograph Series, no. 9. Washington: American Association of Mental Deficiency, 1987.

Expanding Options for Older Adults with Developmental Disabilities: A Practical Guide for Community Access by M. Stroud, E. Sutton, and R. Roberts. Baltimore, MD: Paul H. Brookes Publishing Co., 1988.

An Orientation to the Older Americans Act by Susan Coombs Ficke (ed.). 2d ed., rev. Washington: National Association of State Units on Aging, 1985.

Reports

National

The Aging and Developmental Disabilities Information Exchange: Demonstration and Model Projects [Quarterly Report] coordinated by Thomas Rose and Matthew P. Janicki. College Park, MD: Center on Aging, The University of Maryland, Spring 1987.

Ethical Dilemmas Encountered in the Care of Those Who Are Mentally Retarded and Also Old by Mary C. Howell. Waltham, MA: The Kennedy Aging Project, Shriver Center, 1987.

A National Directory of Programs Serving Elderly Mentally Retarded Persons by Marty W. Krauss and Marsha Mailick Seltzer. Waltham, MA: Starr Center for Mental Retardation, Heller School, Brandeis University, 1986.

A National Profile of Projects and Studies on Aging/Aged Persons with Developmental Disabilities by B.A. Hawkins and S.J. Eklund. Bloomington, IN: Indiana University Developmental Training Center, 1986.

State

Arizona

Interagency Work Group Report on Aging and Developmental Disabilities by G. Roach. Flagstaff, AZ: Arizona Division of Developmental Disabilities, 1987.

Maryland

Aging and Developmental Disabilities: Research and Planning. Final Report to the Maryland State Planning Council on Developmental Disabilities by Thomas Rose and Edward F. Ansello. College Park, MD: National Center on Aging and Disabilities, Center on Aging, The University of Maryland, April 1987.

Mississippi

Services for Elderly Mentally Handicapped Mississippians: A Coordinated Plan by P.D. Cotten, C.R. Britt, and A. Moreland. Sanatorium, MS: Mississippi Department of Mental Health, Boswell Retardation Center, 1986.

New York

Report of the Commissioner's Committee on Aging and Developmental Disabilities. Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities, 1983.

Barriers to and Strategies for the Integration of Older Persons with Developmental Disabilities within Aging Network Services. A Component Report of the Project "Testing the Feasibility of Adapting Aging Network Programs to Serve Older Persons with Developmental Disabilities." Albany, NY: New York State Office for the Aging, June 1987.

Program Alternatives for Frail Elderly and Medically Fragile. Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities, 1987.

Ohio

Older Adults with Mental Retardation and Developmental Disabilities by E.L. Pederson. Cincinnati, OH: University of Cincinnati Center for Developmental Disabilities.

Pennsylvania

A Background Report on Services for the Elderly Mentally Retarded by Glen L. Dunbar. Harrisburg, PA: Pennsylvania Department of Aging.

Articles and Papers

"Aging and Developmental Disabilities" by Thomas Rose and James Linz. **Journal of Contemporary Long-Term Care** (September 1987).

"The Aging Developmentally Disabled Person: A Review" by Thomas Walz, Dennis Harper, and John Wilson. **The Gerontologist** 26, no. 6 (1986) :622-629.

"Disabled and Older People Have an Effective Role as Human Service Providers" by Carol Schreter and Steven W. Brummel. The Elder Press Occasional Paper Series, no. 707. Palm Springs, CA: The Elder Press, 1987.

Educational Gerontology. An International Bimonthly Journal. Special Issue on Aging and Disabilities 14, no. 5 (October 1988). Thomas Rose and Edward F. Ansello, Guest Editors.

"The Elderly Mentally Retarded: A Group in Need of Service" by Marcia Mailick Seltzer and Gary B. Seltzer. **Journal of Gerontological Social Work** 8 (1985): 99-119.

"Growing Old: Responding to the Needs of Older and Developmentally Disabled Persons. Suggestions for Council Activities and State Plan Development in the Area of Aging and Developmental Disabilities" by Matthew P. Janicki. Paper prepared for the use of the National Association of Developmental Disabilities Councils. Washington: The Joseph P. Kennedy, Jr. Foundation, June 1986.

"Growing Old: Responding to the Needs of Older and Elderly Persons with Developmental Disabilities. Suggestions for State and Area Agencies' Activities in the Area of Aging and Developmental Disabilities" by Matthew P. Janicki. Paper presented at the annual training conference of the National Association of State Units on Aging and National Association of Area Agencies on Aging, Seattle, August 1986. Washington: The Joseph P. Kennedy, Jr. Foundation, August 1986.

"Improving Lives and Reducing Expenditures: Medicaid's Agenda for Developmentally Disabled People" by Susan Axelroad and Judith Miller Jones. Issue Brief, no. 464. Washington: National Health Policy Forum, The George Washington University, April 1987.

"It's Not Too Late. An Exercise Program for Older Adults in Special Olympics." Waltham, MA: The Kennedy Aging Project, Shriver Center.

"Long-Term Care Policy and Interest Group Struggles" by Fernando Torres-Gil and Jon Pynoos. **The Gerontologist** 26, no. 5 (1986): 488-495.

"Mental Health and Aging" by Mary S. Harper. **Aging Network News** 3, no. 12 (April 1987): 1, 10, 14.

"The Network on Aging Can Serve Developmentally Disabled Older Adults" by Thomas Rose. **Aging** no. 356 (Summer 1987).

"Older Developmentally Disabled Adults: A Forgotten Population" by Thomas Rose and Matthew P. Janicki. Part 1. **Aging Network News** 3, no. 5 (September 1986): 1, 18-19.

"Older Developmentally Disabled Adults: A Call for Partnership" by Thomas Rose and Matthew P. Janicki. Part 2. **Aging Network News** 3, no. 6 (October 1986): 13-14.

"Services for Persons with Mental Retardation and Developmental Disabilities: Background information and Discussion of Issues" by Mary F. Smith and Richard Price. Paper prepared for the use of the Senate Committee on Aging. Washington: Congressional Research Service, The Library of Congress, 16 September 1986.

"State-administered Programs for Persons with Mental Retardation/Developmental Disabilities: An Overview" by Ruth Katz. Paper prepared for The Johnson Foundation Windspread Conference on Aging and Lifelong Disabilities: Partnership for the Twenty-first Century, Racine, Wisconsin, June 1987. Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc., May 1987.

Video

"Aging...A Shared Experience," by Matthew P. Janicki (producer). Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities, 1988.

"I Should Know A Lot, I Been Around So Long: Stories of People with Mental Retardation Who Have Lived Long Lives," by Mary C. Howell (producer/editor). Waltham, MA: Kennedy Aging Project, Shriver Center for Mental Retardation, 1987.

The Wingspread Conference

Conference Sponsors

The National Center on Aging and Disabilities of The University of Maryland Center on Aging

National Association of State Units on Aging

National Association of State Mental Retardation Program Directors, Inc.

Joseph P. Kennedy, Jr. Foundation

Elvirita Lewis Foundation

The Keland Endowment Fund of The Johnson Foundation

The Pew Charitable Trusts

Retirement Research Foundation

President's Committee on Mental Retardation

National Institute on Aging

78

Wingspread Conference Planning Committee

MEMBERS

Edward F. Ansello, Ph.D.
Conference Co-Director and Acting Director
Center on Aging
The University of Maryland
College Park, Maryland

Thomas Rose, Ph.D.
Conference Co-Director and Research Associate
Center on Aging
The University of Maryland
and
Coordinator
Aging and Disability Program
Montgomery College
Rockville, Maryland

Sara C. Aravanis
Director
Center for State Action on Elder Rights
National Association of State Units on Aging
Washington, D.C.

Frances F. Butler
Washington Representative
The Elvirita Lewis Foundation
Washington, D.C.

Matthew P. Janicki, Ph.D.
Director of Aging Services
New York State Office of Mental Retardation and Developmental Disabilities
Albany, New York

Ruth Katz
Assistant Executive Director
National Association of State Mental Retardation Program Directors, Inc.
Alexandria, Virginia

Theresa N. Lambert
Director of Development
National Association of State Units on Aging
Washington, D.C.

Elizabeth P. Rouse
Associate Director of Program Development
The Joseph P. Kennedy, Jr. Foundation
Washington, D.C.

Harry Walker
Policy Associate
National Association of State Units on Aging
Washington, D.C.

George A. Zitnay
Director of Program Development
The Joseph P. Kennedy, Jr. Foundation
Washington, D.C.

Susan Coombs Ficke
Editorial Consultant
Arlington, Virginia

Speakers

Edward F. Ansello, Ph.D.
Acting Director
Center on Aging
The University of Maryland
College Park, Maryland

Sara C. Aravanis
Director
Center for State Action on Elder Rights
National Association of State Units on Aging
Washington, D.C.

B. Stockton Clark
Director
Program Initiatives Unit
New York State Office for the Aging
Albany, New York

Paul D. Cotten
Director
Boswell Retardation Center
Mississippi Department of Mental Health
Sanatorium, Mississippi

M. Doreen Croser
Assistant Director
Developmental Disabilities Administration
Maryland Department of Health
and Mental Hygiene
Baltimore, Maryland

Jean K. Elder, Ph.D.
Acting Assistant Secretary for
Human Development Services
U.S. Department of Health and Human Services
Washington, D.C.

Robert M. Gettings
Executive Director
National Association of State Mental Retardation
Program Directors, Inc.
Alexandria, Virginia

Julie Ann Jackson
Special Projects Consultant
California Department of Developmental Services
Sacramento, California

Donna McDowell
Director
Wisconsin Bureau on Aging
Second Vice President
National Association of State Units on Aging
Madison, Wisconsin

Jack Ossofsky
President
The National Council on the Aging, Inc.
Washington, D.C.

Janet Pisaneschi, Ph.D.
Health Policy Fellow
Health Office of the Senate Committee on Labor
and Human Resources
U.S. Senate
Washington, D.C.

Marsha Mailick Seltzer, Ph.D.
Associate Professor
School of Social Work
Boston University
Boston, Massachusetts

John L. Stokesberry
Program Director
Southeast Florida Center on Aging
Florida International University
North Miami, Florida

Discussion Leaders, Moderators, and Resource Persons

Edward F. Ansello, Ph.D.
Acting Director
Center on Aging
The University of Maryland
College Park, Maryland

Sara C. Aravanis
Director
Center for State Action on Elder Rights
National Association of State Units on Aging
Washington, D.C.

B. Stockton Clark
Director
Program Initiatives Unit
New York State Office for the Aging
Albany, New York

Robert M. Gettings
Executive Director
National Association of State Mental Retardation Program Directors, Inc.
Alexandria, Virginia

Matthew P. Janicki, Ph.D.
Director of Aging Services
New York State Office of Mental Retardation and Developmental Disabilities
Albany, New York

William E. Jones
Executive Director
American Association of University Affiliated Programs
Silver Spring, Maryland

Donna McDowell
Director
Wisconsin Bureau on Aging
Second Vice President
National Association of State Units on Aging
Madison, Wisconsin

Cathy Michaelson
Coordinator
National Institute on Community-Based Long Term Care
The National Council on the Aging, Inc.
Washington, D.C.

Marilyn Moon
Director
Public Policy Institute
American Association of Retired Persons
Washington, D.C.

Thomas Rose, Ph.D.
Research Associate
Center on Aging
The University of Maryland
College Park, Maryland

Elizabeth P. Rouse
Associate Director of Program Development
The Joseph P. Kennedy, Jr. Foundation
Washington, D.C.

Marsha Mailick Seltzer, Ph.D.
Associate Professor
School of Social Work
Boston University
Boston, Massachusetts

John L. Stokesberry
Program Director
Southeast Florida Center on Aging
Florida International University
North Miami, Florida

Colleen Wieck, Ph.D.
Executive Director
Minnesota Governor's Planning Council on Developmental Disabilities
St. Paul, Minnesota

The Conference Program

The Johnson Foundation Wingspread Conference on Aging and Lifelong Disabilities: Partnership for the Twenty-First Century

June 23-25, 1987
Racine, Wisconsin

Tuesday, June 23, 1987

WELCOME AND OPENING ADDRESSES
RICHARD KINCH / Program Associate, The Johnson Foundation
THOMAS ROSE / Conference Co-director and Research Associate, Center on Aging, The University of Maryland
EDWARD F. ANSELLO / Conference Co-director and Acting Director, Center on Aging, The University of Maryland
JEAN K. ELDER / Acting Assistant Secretary for Human Development Services, U.S. Department of Health and Human Services
JACK OSSOFSKY / President, The National Council on the Aging, Inc.

Wednesday, June 24, 1987

PLENARY SESSION

Introduction to Aging and Lifelong Disabilities

MARSHA MAILICK SELTZER / Associate Professor, School of Social Work, Boston University

Barriers and Opportunities to Cooperation between the Aging and Developmental Disabilities Service Delivery Systems

ROBERT M. GETTINGS / Executive Director, National Association of State Mental Retardation Program Directors, Inc.

State Partnerships to Enhance the Quality of Life of Older Americans with Lifelong Disabilities

SARA C. ARAVANIS / Director, Center for State Action on Elder Rights, National Association of State Units on Aging

ISSUES AND STRATEGIES DISCUSSION GROUPS: PROBLEMS, DILEMMAS, AND BARRIERS

GROUP Ia: Management and Administration
GROUP IIa: Service Systems Development
GROUP IIIa: Advocacy and Public Awareness
GROUP IVa: Policy

LUNCHEON

DISCUSSION GROUP REPORTS: PROBLEMS, DILEMMAS, AND BARRIERS

PLENARY SESSION

Best Practice for Integrating Service Delivery to Older Persons with Developmental Disabilities

JOHN L. STOKESBERRY / Program Director, Southeast Florida Center on Aging, Florida International University

STATE STRATEGIES

ISSUES AND STRATEGIES DISCUSSION GROUPS: STRATEGIES AND RECOMMENDATIONS

GROUP Ib: Management and Administration
GROUP IIb: Service Systems Development
GROUP IIIb: Advocacy and Public Awareness
GROUP IVb: Policy

DINNER

MUSICAL INTERLUDE
The Prairie School Chamber Music Institute

Thursday, June 25, 1987

PLENARY SESSION

Federal Legislation and Strategies for the Future: A View from the Senate

JANET PISANESCHI / Health Policy Fellow, Health Office of the Senate Subcommittee on Labor and Human Resources, U.S. Senate

DISCUSSION GROUP REPORTS: STRATEGIES AND RECOMMENDATIONS

A NATIONAL AGENDA FOR THE FUTURE: ACTION STEPS AND RECOMMENDATIONS

ROBERT M. GETTINGS / Executive Director, National Association of State Mental Retardation Program Directors, Inc.

DONNA MCDOWELL / Director, Wisconsin Bureau on Aging and Second Vice President, National Association of State Units on Aging

LUNCHEON

Conference Participants

ALABAMA
Ray Owens
Director
Mental Retardation Community Programs
Alabama Department of Mental Health and Mental Retardation
Montgomery, Alabama

ARIZONA
Ronald S. Barber
Assistant Director
Arizona Department of Economic Security
Division of Developmental Disabilities
Phoenix, Arizona

CALIFORNIA
Julie Ann Jackson
Special Projects Consultant
California Department of Developmental Services
Sacramento, California

CONNECTICUT
Christina B. Edelwich
Assistant Director for Strategic Planning
Connecticut Department of Mental Retardation
East Hartford, Connecticut

DELAWARE
Eleanor L. Cain
Director
Delaware Division of Aging
New Castle, Delaware

Thomas Pledgie
Director
Delaware Division of Mental Retardation
Dover, Delaware

FLORIDA
Margaret Lynn Duggar
Program Staff Director
Aging and Adult Services
Florida Department of Health and Rehabilitative Services
Tallahassee, Florida

David H. Rodriguez
Client Programs Administrator
Developmental Services Program Office
Florida Department of Health and Rehabilitative Services
Tallahassee, Florida

ILLINOIS
Laura B. Shoot
Planner
Division of Long Term Care
Illinois Department on Aging
Springfield, Illinois

INDIANA
Cynthia Wagner
Program Coordinator
Pre-admission Screening Program
Indianapolis, Indiana

IOWA
Dennis C. Harper, Ph.D.
Supervisor, Psychological Services
Division of Developmental Disabilities
University Hospital School
University of Iowa
Iowa City, Iowa

KENTUCKY
Charles E. Bratcher
Director
Kentucky Department for Mental Health and Mental Retardation Services
Division of Mental Retardation
Frankfort, Kentucky

MAINE
Betsy J. Davenport
Director
Bureau of Mental Retardation
Maine Department of Mental Health and Mental Retardation
Augusta, Maine

Christine Gianopoulos
Acting Director
Bureau of Maine's Elderly
Maine Department of Human Services
Augusta, Maine

MARYLAND
M. Doreen Croser
Assistant Director
Developmental Disabilities Administration
Maryland State Department of Health and Mental Hygiene
Baltimore, Maryland

MICHIGAN

Irene Kazieczko
Older Adult Specialist
Michigan Department of Mental Health
Lansing, Michigan

Olivia P. Maynard
Director
Michigan Office of Services to the Aging
Lansing, Michigan

MINNESOTA

Edward R. Skarnulis
Director
Minnesota Department of Human Services
Mental Retardation Division
St. Paul, Minnesota

MISSISSIPPI

David K. Brown, Ph.D.
Director
Mississippi Council on Aging
Jackson, Mississippi

Paul D. Cotten, Ph.D.
Director
Boswell Retardation Center
Mississippi Department of Mental Health
Sanatorium, Mississippi

MISSOURI

Cleophus Jones
Assistant to the Director
Missouri Division on Aging
Jefferson City, Missouri

NEBRASKA

Chip Black
Program Specialist
Nebraska Department on Aging
Lincoln, Nebraska

James L. Wiley
Deputy Director
Nebraska Department of Public Institutions
Lincoln, Nebraska

NEW YORK

B. Stockton Clark
Director
Program Initiatives Unit
New York State Office for the Aging
Albany, New York

Matthew P. Janicki, Ph.D.
Director of Aging Services
New York State Office of Mental Retardation and Developmental Disabilities
Albany, New York

NORTH CAROLINA

Don E. Taylor
Director for Mental Retardation
North Carolina Department of Human Resources
Division of Mental Health and Mental Retardation Services

NORTH DAKOTA

Larry Brewster
Director
Aging Services
North Dakota Department of Human Services
Bismarck, North Dakota

OHIO

Kim Linkinhoker
Chief
Office of Adult Services
Ohio Department of Mental Retardation and Developmental Disabilities

OKLAHOMA

Hannah D. Atkins
Assistant Director
Oklahoma Department of Human Services
Aging Services Division
Oklahoma City, Oklahoma

OREGON

Susan L. Dietsche
Assistant Administrator
Oregon Senior Services Division
Salem, Oregon

PENNSYLVANIA

Glen L. Dunbar
Director of Policy, Planning and Research
Pennslyvania Department of Aing
Harrisburg, Pennsylvania

RHODE ISLAND

Ann Marie Swiszcz
Rhode Island Department of Elderly Affairs
Representative
Rehabilitation Supervisor
IN-SIGHT
Programs in Productive Living for the Blind
Warwick, Rhode Island

SOUTH CAROLINA
Ruth Q. Siegler
Executive Director
South Carolina Commission on Aging
Columbia, South Carolina

SOUTH DAKOTA
Patti Miles
Program Specialist
Office of Developmental Disabilities and Mental Health
South Dakota Department of Social Services
Pierre, South Dakota

TENNESSEE
James Foshee, Ph.D.
Assistant Commissiner for Mental Retardation Services
Tennessee Department of Mental Health and Mental Retardation
Nashville, Tennessee

UTAH
Sally Anne Brown
Program Specialist
Utah Department of Social Services
Division of Aging and Adult Services
Salt Lake City, Utah

WASHINGTON
Kevin Krueger
Program Planner
Washington State Department of Social Services
Aging and Adult Services Administration
Olympia, Washington

WISCONSIN
Dennis Harkins
Director
Developmental Disabilities Office
Wisconsin Department of Health and Social Services
Madison, Wisconsin

Donna McDowell
Director
Bureau on Aging
Wisconsin Department of Health and Social Services
Division of Community Services
Madison, Wisconsin

WYOMING
Margaret A. Auker
Deputy Director
Wyoming Commission on Aging
Cheyenne, Wyoming

National Organization Representatives and Invited Guests

Sara C. Aravanis
Director
Center for State Action on Elder Rights
National Association of State Units on Aging
Washington, D.C.

Jean K. Elder, Ph.D.
Acting Assistant Secretary for Human Development Services
U.S. Department of Health and Human Services
Washington, D.C.

Robert M. Gettings
Executive Director
National Association of State Mental Retardation Program Directors, Inc.
Alexandria, Virginia

Mary S. Harper, Ph.D.
Coordinator
Long Term Care Programs
National Institute of Mental Health
Mental Disorders of Aging Research Center
Rockville, Maryland

William E. Jones
Executive Director
American Association of University Affiliated Programs
Silver Spring, Maryland

Mary A. Marshall
Member
Virginia House of Delegates
Chairman of the Task Force on Long Term Care
National Conference of State Legislators
Arlington, Virginia

Cathy Michaelson
Coordinator
National Institute on Community-based Long Term Care
The National Council on the Aging, Inc.
Washington, D.C.

Marilyn Moon
Director
Public Policy Institute
American Association of Retired Persons
Washington, D.C.

Jack Ossofsky
President
The National Council on the Aging, Inc.
Washington, D.C.

Janet Pisaneschi
Health Policy Fellow
Health Office of the Senate Committee on Labor and Human Resources
U.S. Senate
Washington, D.C.

Elizabeth P. Rouse
Associate Director of Program Development
The Joseph P. Kennedy, Jr. Foundation
Washington, D.C.

Marcia Mailick Seltzer, Ph.D.
Associate Professor
School of Social Work
Boston University
Boston, Massachusetts

John L. Stokesberry
Program Director
Southeast Florida Center on Aging
Florida International University
North Miami, Florida

Colleen Wieck, Ph.D.
Executive Director
Minnesota Governor's Planning Council on Developmental Disabilities
St. Paul, Minnesota

Conference Recorders

Audrey L. Begun, Ph.D.
Professor of Social Work
School of Social Welfare
University of Wisconsin-Milwaukee

William H. Koch, Ph.D.
Professor
Center for Adult Development
Division of Outreach and Continuing Education
University of Wisconsin-Milwaukee
Milwaukee, Wisconsin

Lynn McMunn
Graduate Student
University of Wisconsin-Milwaukee
Watertown, Wisconsin

Jill Niesen
Graduate Student
University of Wisconsin-Milwaukee
Watertown, Wisconsin

Betty Sancier, Ph.D.
Director
Center for Adult Development
Division of Outreach and Continuing Education
University of Wisconsin-Milwaukee
Milwaukee, Wisconsin

The Johnson Foundation Wingspread Center

Richard Kinch
Program Associate
The Johnson Foundation
Racine, Wisconsin

Kay Mauer
Conference Coordinator
The Johnson Foundation
Racine, Wisconsin

Paula L. Howard
Wingspread Fellow and Undergraduate Student
Northwestern University
Evanstop, Illinois

Robin L. White
Wingspread Fellow and Undergraduate Student
University of Wisconsin-Parkside
Kenosha, Wisconsin

The National Center on Aging and Disabilities was created in 1985 by The University of Maryland Center on Aging to focus attention on the growing population of older Americans with lifelong disabilities and their unique needs. Its studies, training and educational programs, and program development activities produce timely and practical information to assist leaders of government and other public policy-makers, administrators, academicians, representatives of professional and public groups, practitioners, scholars, students, and concerned citizens in arriving at sound decisions so necessary to the well-being of America's elderly with lifelong disabilities. The Center's purpose is to understand better the policy and practice implications and service requirements attendance upon the increased longevity of developmentally disabled and mentally retarded citizens.

Additional copies of this report may be obtained from The University of Maryland Center on Aging at $10.00 each (postage paid).

The National Center of Aging and Disabilities
Center on Aging
The University of Maryland
College Park, Maryland 20742-2611
Telephone: (301) 454-5856

The National Center on Aging and Disabilities
Center on Aging
The University of Maryland
Room 1120, Francis Scott Key Hall
College Park, Maryland 20742-7321

Graphics and Printing by ELDER PRESS

ISBN 0-924840-00-5

85